



Walden University
ScholarWorks

Walden Dissertations and Doctoral Studies

Walden Dissertations and Doctoral Studies
Collection

2019

Recommendations for African American Family Caregivers of Adult with Congestive Heart Failure.

Callista Chika Ejim
Walden University

Follow this and additional works at: <https://scholarworks.waldenu.edu/dissertations>



Part of the [Nursing Commons](#)

This Dissertation is brought to you for free and open access by the Walden Dissertations and Doctoral Studies Collection at ScholarWorks. It has been accepted for inclusion in Walden Dissertations and Doctoral Studies by an authorized administrator of ScholarWorks. For more information, please contact ScholarWorks@waldenu.edu.

Walden University

College of Health Sciences

This is to certify that the doctoral study by

Callista Ejim

has been found to be complete and satisfactory in all respects,
and that any and all revisions required by
the review committee have been made.

Review Committee

Dr. Courtney Nyange, Committee Chairperson, Nursing Faculty

Dr. Anne Vitale, Committee Member, Nursing Faculty

Dr. Joan Moon, University Reviewer, Nursing Faculty

The Office of the Provost

Walden University
2019

Abstract

Recommendations for African American Family Caregivers of
Adults with Congestive Heart Failure

by

Callista Chika Ejim

MS, Walden University, 2014

BS, University of Texas at Arlington, 2005

Project Submitted in Partial Fulfillment
of the Requirements for the Degree of
Doctor of Nursing Practice

Walden University

August 2019

Abstract

African Americans suffer disproportionately higher incidence of congestive heart failure (CHF) at an earlier age of onset and with more rapid progression compared to other races. Due to this escalating prevalence of CHF within the African American population and the lack of culturally responsive support for the caregiving role, African American family caregivers of adult CHF patients face greater challenges and suffer increased caregiver burden, stress, depression, and financial strain compared to European American caregivers. The purpose of this project was to conduct a systematic literature review to find the recommendations that target African American family caregivers of adult CHF patients. The Joanna Briggs Institute model for systematic review (JBIM-SR), and the caregiver stress theory proposed by Tsai, guided this project. A review of multiple databases yielded 118,078 articles. After removal of duplicates and exclusion of articles not consistent with the purpose of the review, 1 article was selected. A second reviewer completed an independent search of the databases using the same exclusion/inclusion criteria and identified the same review. The selected article was analyzed and graded using the JBIM-SR grading tools. Family Heart Failure Home Care, a telephone coaching intervention adapted to the cultural preferences of the African American family caregivers of adult CHF patients, was suggested as an effective culturally sensitive intervention. Results of this project can promote positive social change by improving the care and well-being of the African American community. Nurses at the project site can use the findings to provide evidence-based care to the African American family caregivers of adult CHF patients.

Recommendations for African American Family Caregivers of
Adults with Congestive Heart Failure

by

Callista Chika Ejim

MS, Walden University, 2014

BS, University of Texas at Arlington, 2005

Project Submitted in Partial Fulfillment
of the Requirements for the Degree of
Doctor of Nursing Practice

Walden University

August 2019

Dedication

This project is dedicated to the numerous family caregivers; especially to the African American family caregivers of adult CHF patients, who labor continuously to care for sick relatives with psychological and physical limitations. Family caregivers save healthcare resources; their contributions to our health care system can never be over-emphasized. As healthcare providers, we should strive to provide evidence-based care to these partners in caring.

Also, to my late parents Mr. & Mrs. Herbert Amadi who instilled in me the love of knowledge and education at an early age. Thank you!

Acknowledgments

First, I would like to acknowledge the grace of God and his son Jesus Christ that made completion of this project possible. I want to recognize my husband, The Traditional Prime Minister of Imerienwe autonomous community (TPM) Sabastine Egwuatuonwu Ejim for his support and for believing in me, even when I had doubts of my abilities. I would like to thank my children, Ozy, Ody, Nonye, Udoka, Chinwe, and Nnanna for their immense support, sacrifice and understanding during this academic journey. I want to give a special thanks to my last son Nnanna Ejim, who served as my technical support throughout this journey. All your late nights were not in vain!

I wish to thank all my professors at Walden University; especially my project committee members, Dr. Anne Vitale, and Dr. Joan Moon; who made contributions to my doctoral work. I appreciate all your guidance during the completion of this project. To my committee chair, Dr. Courtney Shante' Nyange, I sincerely appreciate your guidance, expertise, patience, and encouragement. Your kind words kept me going at the most difficult times. Finally, I would like to thank all my mentors and preceptors, Dr. Petua Okolo, Dr. George Okolo, and Dr. Kara Sellers for sharing their expertise.

Table of Contents

Section 1: Nature of the Project	1
Introduction	1
Problem Statement	3
Local Context for Gap in Practice	5
Local Relevance and Practice Environment	7
Significance and Implications for Nursing Practice	8
Purpose Statement	10
Practice-Focused Question	11
Potential to Address Gap in Practice	11
Nature of the Doctoral Project	11
Project's Sources of Evidence	12
Project Method	13
Significance	13
Stakeholders	14
Contribution to Nursing Practice	15
Transferability of Knowledge	15
Implication for Positive Social Change	16
Summary	18
Section 2: Background and Context	20
Introduction	20
Concepts, Models, and Theories	22

JBIM-SR	22
Theory of Caregiver Stress	23
Definition of Terms.....	26
Project Relevance to Nursing Practice.....	29
A Brief History of the Broader Problem in Nursing Practice.....	29
Overview of the Literature.....	30
Evidence to Address the Gap in Practice.....	34
Local Background and Context	35
Evidence to Justify Project Problem.....	35
Institutional Context.....	36
Role of the DNP Student.....	37
Motivation for Completing the Project.....	37
Potential Bias	38
Role of the Project Team	38
Team Member Expertise and Contextual Insight	38
Team Members' Responsibilities and Timeline	39
Summary.....	40
Section 3: Collection and Analysis of Evidence.....	41
Introduction.....	41
Practice-Focused Question.....	41
Project Purpose and Method Alignment.....	42
Sources of Evidence.....	44

Published Outcomes and Research	44
Relationship of the Evidence to the Purpose	44
Evidence to Address the Practice-Focused Question.....	45
Literature Search Strategy.....	45
The Scope of the Review	46
Search Exhaustive and Comprehensive	47
Institutional Review Board	47
Analysis and Synthesis	47
Data Systems and Procedures	48
Data Integrity	48
Data Analysis	48
Summary	49
Section 4: Findings and Recommendations	50
Introduction.....	50
Findings.....	52
Implications.....	56
Recommendations.....	56
Contributions of the Doctoral Project Team	58
Strengths and Limitations of the Project.....	58
Summary and Conclusions	59
Section 5: Dissemination Plan	60
Introduction.....	60

Analysis of Self.....	60
Summary	61
References	62
Appendix A: MASTARI Data Extraction Tool	80
Appendix B: JBIM Grading Chart.....	81
Appendix C: JBIM Levels of Evidence for Effectiveness.....	82
Appendix D: PRISMA.....	83
Appendix E: Literature Review Matrix	84
Appendix F: FamHFcare.....	85

Section 1: Nature of the Project

Introduction

Congestive heart failure (CHF) is an increasingly prevalent chronic condition associated with high morbidity and mortality (Benjamin et al., 2017). African Americans have the highest prevalence of CHF as well as a higher risk of CHF-related morbidity, mortality, and hospitalization compared to the general population (Dickson, Knafl, Wald, & Riegel, 2015). The trajectory of CHF is uniquely characterized by periods of stability, interspersed with occasional, unexpected, acute exacerbations that requires hospital admission and readmission (Arundel et al., 2018; Hamilton, 2016). Patients with CHF often experience compromised psychological, physiological, and functional abilities, as well as lifestyle and independence status that warrant the continual assistance of a family caregiver (Akosile, Okoye, Nwankwo, & Mbada, 2011; Dionne-Odom et al., 2017; Evangelista, Stromberg, & Dionne-Odom, 2016; Mashayekhi, Pilevarzadeh, & Rarati, 2015).

Most family caregivers are not adequately prepared for the role of caregiving and often lack the support and resources needed for their role (Graspa et al., 2014). The lack of support ultimately impacts the physical and psychological well-being of family caregivers (Söylemez, Küçükgülü, & Buckwalter, 2016; Tsai, 2003), as well as cause emotional and financial strain (National Academies of Science, Engineering, and Medicine, 2016). Supporting family caregivers with evidence-based interventions is crucial for their well-being (Evangelista et al., 2016). According to Söylemez et al. (2016), psychosocial support interventions, such as services that focus on increasing

family caregivers' coping skills, can yield reduced depression, stress, and caregiver burden.

African American family caregivers are unique in their need as caregivers because they are affected differently by the caregiving role (Wells et al., 2017). Being African American is associated with low educational level, lower socio-economic status, and stronger cultural and family ties compared to the general population (Gary et al., 2018; Wells et al., 2017). African American family caregivers are less likely than other ethnic groups to use available traditional resources (Flores, & Lin, 2013). Researchers have found that African American family caregivers suffer more from health disparities and have unique symptomology and response to interventions (Gary et al., 2018; Wells et al., 2017). Ethnicity is a strong variable in the caregiving burden continuum (Gary et al., 2018). A sense of filial responsibility and familism is higher in African American family caregivers compared to their European American counterparts (McCleary, & Blain, 2013; Richardson et al., 2017). Although it has been reported that African American family caregivers have moderate to low emotional stress, financial strain, and psychological distress due to their caregiving role compared to European Americans (National Alliance on Caregiving, 2015), other researchers have attributed this findings to lack of adequate appraisal of the caregiving role, positive religious coping, and cultural factors that encourage resilience (Merritt McCallum, 2013).

The current body of knowledge regarding the need of family caregivers has been derived mostly from European American family caregivers of patients with Alzheimer's disease, dementia, stroke and cancer, and has failed to provide the information needed to

support African American family caregivers of adults with CHF (Graham-Phillips, Roth, Huang, Dilworth-Anderson, & Gitlin, 2016; Hamilton, 2016; Lahaie, Earle, & Heyman, 2012; Thornton & Hopp, 2011). Thus, there is an increased need for research with people of African American ethnicity caring for CHF patients and on their caregiving needs.

This project was a systematic literature review in which I explored the literature for interventions specific to African American family caregivers of adults with CHF.

Information gathered was expected to help in developing evidence-based support strategies and recommendations for African American family caregivers of adults with CHF. The project supported positive social change by assessing the state of current evidence-based support for African American family caregivers of adults with CHF with the hope of improving the lives of this population of caregivers and their sick relatives.

Problem Statement

African Americans have the highest prevalence of CHF as well as a higher risk of CHF-related morbidity, mortality, hospitalization and rehospitalization and are in greater need for a family caregiver than their European American counterparts (Dickson et al., 2015). African American family caregivers are noted to have unique cultural needs.

Richardson et al. (2017) noted that African American family caregivers have different experiences in caregiving at the environmental, intrapersonal, and interpersonal levels.

The authors also identified different experiences in their caregiving appraisal, coping, filial responsibility, spirituality, physical function, familism, social support utilization, and use of health-related resources (Pharr, Francis, Terry, & Clark, 2014; Richardson et al., 2017). Culture and social norms interfere with caregiving experience by creating a

“selectivity” about whom the caregiver confides in, as well as the willingness to access available support. Thus, family caregivers with strong cultural influence can experience social isolation (Dickson, McCarthy, Howe, Schipper, & Katz, 2013).

Furthermore, African Americans have low educational status that affects their caregiving capabilities and use of available resources (Flores & Lin, 2013). Caregivers with low educational attainment are known to provide lower quality care (Terayama, Sakurai, Namioka, Jaime, & Hangu, 2018). According to Karakurt, Unsal, and Tanriverdi (2018), illiterate caregivers have a higher burden of caregiving compared to those who are literate. Thus, African American family caregivers suffer disproportional disparity in health due to cultural values and low educational levels and should be supported with physical and psychosocial resources (Karakurt et al., 2018; Rowland, & Isaac-Savage, 2014; Reinhart, Givens, Petlick, & Bernis (2014)).

A review of the literature revealed that most studies on family caregivers were done with the European American population of differing diseases such as Alzheimer's, dementia, stroke, and cancer (Dickson et al., 2015; Rowland, & Isaac-Savage, 2014; Terayanna et al., 2018). CHF is different from other chronic diseases in terms of trajectories, signs and symptoms, treatment options, prognosis and stigmatization (Cagle et al., 2017). Additionally, the population affected by other chronic diseases are unique in many fundamental ways compared to CHF patients (Honary et al., 2018). It is not known if research completed with European American family caregivers of CHF patients can be safely extrapolated on their African American counterparts. Considering these

differences, it is reasonable to assume that adult CHF patients and their family caregivers have a distinct set of needs that should be explored by nurses.

Studies on African American family caregivers of adults with CHF are limited, and little to no attention has been given to the patient outcome when family caregivers are the target of intervention (Sullivan et al., 2018). Nursing lacks evidence-based recommendations and strategies to care for African American family caregivers of adult CHF patients. There is a need to explore culturally and cognitively appropriate, evidence-based strategies and recommendations focused on supporting African American family caregivers of adult CHF patients in their role. The purpose of this DNP project was to conduct a systematic literature review of studies focused on African American family caregivers of adults with CHF to identify the evidence-based recommendations available to clinicians to provide the relevant cultural, educational, and psychosocial care and empower African American family caregivers in their role.

Local Context for Gap in Practice

The project site was a 537-bed county hospital in a rural region of the southern United States. The site was in an area designated by the U.S Health Resources and Services Administration (2018) as a medically underserved area. The regional uninsured rate was estimated at 76.4% (Berchick, Hood, & Barnett, 2018). The project site served a large population of African American adults with CHF and their families. Mohan and Fox (2011) found that the rate of hospitalization for African American CHF patients was estimated at 959 per 100,000 people, which is almost three times the rate of their European American counterparts at 349 per 100,00 people. African Americans suffer a

disproportionate burden of disease related to CHF and do not have similar benefits of treatment to that of their European American counterparts (Hamilton, 2016).

According to the American Heart Association (2014), 5.6 % of African Americans are diagnosed with CHF compared to 2.4 % of European Americans. Before the age of 50, African Americans' CHF rate is 20 times greater than that of European Americans, and they are more likely to die from complications than their European American counterparts (Sharman, Colvin-Adams, & Yancy, 2014). Thus, CHF among African Americans is more prevalent, has an earlier onset, and has more severe consequences than in European Americans. With high uninsured rates, large proportions of adult patients with CHF in the project site were discharged to their homes instead of to an ancillary facility, and they required the help of a family caregivers.

The current practice at the project site was to offer little to no care to African American family caregivers of adult CHF patients. When nurses attempted to give care to this population, they resort to “standard care” developed for the European American family caregivers of cancer, stroke, Alzheimer, and dementia patients (Hamilton, 2016). The director of nursing at the project site agreed that the current modality of care lacks cultural tailoring and has been inadequate in caring for the African American family caregiver of an adult with CHF. According to Jha and Epstein (2012), most leaders of minority-populated hospitals are unaware that culturally unresponsive care exists in their organization. The trend of disregarding the cultural and cognitive needs of African American family caregivers of adult CHF patients is problematic and needs to be addressed. Lack of explicit attention to African American family caregivers of adults

with CHF in the project site was a serious gap in quality care for this population. The purpose of this systematic review was to gather evidence-based recommendations for the care of African American family caregivers of adult CHF patients.

Local Relevance and Practice Environment

CHF is a chronic and debilitating disease, with high rates of mortality and morbidity (Benjamin et al., 2017). African Americans bear a disproportionate burden of the disease (Thornton & Hopp, 2011). Poorly managed CHF negatively impacts patients' lives and can lead to diminished quality of life, early mortality, frequent rehospitalization, difficulty completing activities of daily living and instrumental activities of daily living (Hamilton, 2016). Many adult CHF patients end up at home needing the help of a family caregiver to maintain a complex regimen associated with CHF management, prevent symptom flare-ups, and reduce hospital readmissions (Roth, Dilworth-Anderson, Huang, Gross, & Gitlin, 2015). Family caregivers of adults with CHF suffer physically and psychologically due to their caregiving roles (Agren, Evangelista, Hjelm, & Stromberg, 2012; Hopps, Ladeluca, McDonald, & Makinson, 2017). Lack of culturally and cognitively responsive interventions at the project site exposed African American family caregivers of adult CHF patients to increased frustration, stress, burden of care, and depression, and decreased quality of life (Söylemez et al., 2016). Also, African American family caregivers experienced role strain, a conflict that threatens their well-being (Burke, Jones, Ho, & Bekelman, 2014; Venetis, Robinson, & Kearney, 2015).

Caregiving experience is affected by ethnic, cultural, racial, and national variations (Sheet, Black, & Kaye, 2014) and there is a need to culturally tailor

interventions as part of evidence-based care (Jordan, Lockwood, Aromataris, & Munn, 2016). Although the role of family caregivers is similar across different ethnic groups, African American family caregivers are unique in certain cultural, educational and socio-economic characteristics (Rowland, & Isaac-Savage, 2014). Reinhard et al. (2014) noted that family caregivers' cultural background, level of knowledge, and the ability to use available resources have a strong reciprocal relationship with their quality of life. But African American family caregivers of adults with CHF at the project site continue to receive care from modalities derived from research with European American family caregivers of stroke, dementia, cancer, and Alzheimer's disease patients (Graham-Phillips et al., 2016; Hamilton, 2016; Lahaie et al., 2012; Thornton & Hopp, 2011). The use of standard care has failed to adequately care for this population. African American family caregivers of adult CHF patients have unique needs that necessitate the adaptation of interventions to their specific needs. At a minimum, providers must offer African American family caregivers of adults with CHF current evidenced-based recommendations that are culturally tailored and cognitively appropriate. The lack of available culturally and cognitively responsive care for African American family caregivers of CHF adults at the project site was a relevant practice problem that warranted attention. It was imperative to explore the evidence-based interventions geared towards African American family caregivers of adults with CHF.

Significance and Implications for Nursing Practice

Nursing is concerned with the provision of culturally tailored care, but nurses at the project site lacked evidence-based resources to care for the African American family

caregivers of adult CHF patients. African American family caregivers of adult CHF patients had variable socio-economic, educational, and cultural barriers that nurses needed to address when providing care. African American adult CHF patients were more likely than their European American counterparts to have no insurance and to have their disease diagnosed at a later stage (Dickson et al., 2015). With late diagnoses and no insurance, African American adults with CHF were more likely than their European American counterparts to end up at home requiring care from an unprepared family caregiver. Financial limitations made it difficult for African American families to pay for services such as cardiac rehabilitation, physical therapy, occupational therapy, skilled nursing facilities, medications, and in-home help (Hamilton, 2016). Thus, African American family caregivers were more likely than other ethnic groups to live with the sick relative and to devote more time to the caregiving function (Thornton & Hopp, 2011). The National Alliance on Family Caregivers (2015) noted that African Americans are the second largest group of family caregivers. Given the increasing dependence on African American family caregivers and the potential harm of caregiving, providing caregivers with evidence-based interventions could improve their skills, confidence, and lower their caregiving burden (Piamjariyakul, Smith, Russell, Werkowitch, & Elyachar, 2013). This project was able to address the lack of evidence-based practice by systematically reviewing scholarly articles to gather appropriate evidence-based recommendations for this population.

Honary, Fisher, McNaney, and Lobban (2018) noted that effective caregiving could reduce the rate of readmission for chronically ill patients. During a recent personal

communication with the director of nursing, she admitted that the 30-day readmission rate for adult CHF patients at the project site is high and affects hospital cost (S. Donald, personal communication, March 20, 2019). Providing African American family caregivers of adult CHF patients with evidence-based recommendations geared towards them should be an integral part of evidence-based care and could help decrease the readmission rate of the CHF patient (McMillian, Small, Haley, Zambroski, & Buck, 2013). Caring for the carer has emerged as one of the central concepts of nursing (National Alliance for Caregiving, 2015).

CHF has reached a global crisis (Thomas, 2017), and its management is crucial. The American Heart Association guidelines recognize the critical need to involve family caregivers in the home management of CHF (Zafar et al., 2016). Family caregivers can provide essential support and help prevent rehospitalization by recognizing worsening symptoms of CHF, such as edema and shortness of breath. But they require education to be alert to these problems (Piamjariyakul et al., 2013). This doctoral project may be of global significance to nursing as it can lead to the development of resources that could help guide nursing practice, enhance understanding of the unique needs of the target population, reduce hospital costs, and empower practitioners to make evidence-based decisions in the care of African American family caregivers of adult CHF patients.

Purpose Statement

African American family caregivers of adult CHF patients at the project site receive care according to the modalities developed for European American family caregivers of patients with other chronic diseases (Hamilton, 2016). Thus, nursing

practice lacks the evidence-based strategies and recommendations needed in the care of African American family caregivers of adult CHF patients (Thornton & Hopp, 2011). Due to gaps in nursing practice in the care of African American family caregivers of adults with CHF, they suffer significant higher burden of the caregiving role compared to their European American counterparts (Burke et al., 2014; Söylemez et al., 2016; Thornton & Hopp, 2011). The purpose of this project was to conduct a systematic literature review to explore, assess, synthesize, and report evidence-based interventions targeted towards African American family caregivers of adults with CHF.

Practice-Focused Question

The practice focused question for this systematic review was as follows: What evidence-based interventions are available to African American family caregivers of adults with CHF to support them in their role?

Potential to Address Gap in Practice

The information from this systematic literature review has the potential to address the gap in practice by providing evidence-based strategies and recommendations needed in the care of the African American family caregiver of adult CHF patients. Also, evidence from this project may provide more understanding of the African American family caregivers' desired needs in caregiving and can improve future interventions targeted towards them.

Nature of the Doctoral Project

Evidence-based practice recommends the cultural tailoring of care to capture the patient's unique context (Jordan et al., 2016). According to Black, Balneaves, Garossino,

Puyat, and Qian (2015), cultural tailoring of care improves patient safety and clinical outcomes. Although differences in family caregivers' experience is documented in the literature (Hamilton, 2016; Sheet et al, 2014.), the extent to which interventions are tailored to address these cultural differences seems to be nonexistent. Supporting African American family caregivers of adult CHF patients with evidence-based recommendations can provide a buffering effect for the caregiving burden (Tsai, 2003). Through this systematic literature review, interventions targeted toward African American family caregivers of adult CHF patients were collated, reviewed, analyzed, and synthesized into evidence-based recommendations for the population and the clinicians that care for them. The nature of this project was to conduct a systematic literature review of high-quality evidence that would assist in developing evidence-based support strategies and recommendations for African American family caregivers of adults with CHF.

Project's Sources of Evidence

Multiple databases were searched including the Cochrane Library, Joanna Briggs Institute's Evidence-Based Practice database of systematic reviews, CINAHL, Clinical Trial.gov, Medline, and PubMed to extract primary, peer-reviewed journal articles. Additionally, official websites such as the American Heart Association and the Heart Failure Society of America were accessed for resources. The practice-focused question guided the inclusion and exclusion criteria, as well as the key words and phrases for the search. A comprehensive search was conducted to find relevant studies within the last 10 years. The article selection procedure followed the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) flowchart (Moher, Liberati, Tetzlaff,

& Altman, 2009). Search results were organized and synthesized using the matrix methodology, which can help to group together relevant concepts related to caring for the African American family caregiver of adult CHF patient (Grove, Burns, & Gray, 2013). The synthesized current knowledge on the focused question was presented in a literature review matrix (See Appendix E).

Project Method

The project was a systematic review; the literature search, data extraction, data synthesis, and quality of studies were appraised using the Joanna Briggs Institute Method for Systematic Reviews (JBIM-SR; Pearson, Wiechula, Court, & Lockwood, 2005). The JBIM-SR has an established pathway for the process of gathering evidence to validate clinical practice changes. Using the JBIM-SR protocol ensured that bias and errors inherent in systematic reviews were minimized. Gaps in the literature were identified, and strengths and weaknesses were summarized. Evidence-based support strategies and recommendations were extracted from the systematic literature review. The evidenced-based recommendations and strategies can be developed into educational material and can be disseminated throughout the healthcare organizations as a resource for nurses caring for African American family caregivers of adults with CHF.

Significance

This systematic literature review of interventions was completed to collate, analyze, and synthesize recommendations and strategies geared toward African American family caregivers of adult CHF patients. This project was significant because it could help nurses provide evidence-based care to African American family caregivers of adult

CHF patients. Thus, the results of this project would help enhance the quality of life and well-being of African American family caregivers of adults with CHF. This project could also increase awareness of the issues that impact African American family caregivers of adults with CHF. Recommendations gathered through this systematic review can be disseminated among health care organizations to help nurses provide appropriate guidance to African Americans in their role as family caregivers to CHF patients. The recommendations can also be culturally adapted to meet the needs of other ethnic family caregivers of adults with CHF.

It is projected that many adults with CHF will live longer, and thus will need the services of a family caregiver as they grow older (McMillian et al., 2013). The increase in the population of adult CHF patients, coupled with the decrease in hospital length of stay, can exacerbate the burden on family caregivers of adult CHF patients. Also, African American family caregivers of adult CHF patients play crucial roles in saving healthcare resources by serving as family caregivers. The results from this project can inform hospital administrators and policy makers of the importance of recognizing the economic values of African American family caregiver of adult CHF patients, and the need to identify recommendations and strategies that can remedy the stress family caregivers face as a result of their role (Burke et al., 2014).

Stakeholders

The stakeholders for this DNP project were the adult CHF patients, the African American family caregivers, the clinicians, and the leadership at the project site. The adult CHF patients may benefit by receiving better management of disease, fewer

symptoms flare-ups, and decreased rehospitalization. The African American family caregiver may have increased caregiving capabilities, less stress, and enhanced quality of life. The clinicians serving this population can have evidence-based guidance in the care of African American family caregivers of adult with CHF. The project site may have decreased 30-day readmission rates for adult CHF patients, meet core measures as stipulated by the Centers for Medicare and Medicaid Services, and boost their financial bottom line.

Contribution to Nursing Practice

This systematic review of high-quality studies specific to African American family caregivers of adults with CHF is intended to be translated into evidence in a format easily accessible to clinicians taking care of adult CHF patients with African American family caregivers. Nurses can adopt the recommendations from this review to gain new knowledge and to offer culturally sensitive care to African American family caregivers of adult CHF patients. Thus, the recommendations from this project have the potential to change clinical practices, enhance patient education, and support transition from intuition-based to evidence-based practice with regard to African American family caregivers of adult CHF patients.

Transferability of Knowledge

The systematic literature review process has a sharp focus on knowledge translation into practice through the synthesis of available information (Jordan et al., 2016). The process facilitates the integration of available research evidence, clinical expertise, and patients' values into clinical decision-making at the point of care (Pearson,

Jordan, & Munn, 2012). Evidence-based practice has been embraced by nursing as a proven method of transferring knowledge. Incorporating evidence-based care into patient care can improve the quality of care and reduce health care costs.

The information garnered through this DNP project can be developed into evidence-based educational materials that nurses may use to care for African American family caregivers of adult CHF patients throughout the hospital as well as through other local healthcare organizations. Evidence-based strategies and recommendations from this systematic review can also serve as a tool to evaluate nurses' knowledge in the care of CHF patients and their family caregivers. Furthermore, information from this project can be developed into electronic media, audio/visual formats, journal articles and shared within African American communities. Through the findings of this project, health care practitioners who provide direct or indirect services to this population may now have the needed evidence-based strategies and recommendation to care for them.

Implication for Positive Social Change

An estimated 23 million persons with CHF worldwide receive care from a family caregiver. This number is projected to increase by 25% by the year 2030 (Heidenreich et al., 2013; National Alliance for Caregiving, 2015). In the United States, family caregivers are valued at an estimated \$522 billion dollars per year (National Alliance for Caregiving, 2015). Since African Americans have the highest incidence and prevalence of CHF, it would be safe to deduce that most family caregivers of adult CHF patients are African Americans. As a result of an aging population, and an increasing number of CHF patients living longer, more African Americans will become family caregivers. There should be a

concomitant increase in the recognition of their caregiver burden and ways to mitigate that burden by nursing (Hopps, et al., 2017). Thus, Foebel, Hindes, & Heckman (2012) advised that health care practitioners recognize African American family caregivers as both co-providers and co-recipients of care alongside their sick relatives. According to Hopps et al. (2017), reducing caregiver burden can benefit the caregiver, the care recipient, and can result in overall improvements in health at the population levels.

This DNP project can enhance positive social change by collating, analyzing, and synthesizing evidenced-based recommendations and strategies that can reduce caregiver stress by directing African American family caregivers to resources. Evidence-based recommendations from this project can also educate family caregivers on how to understand clinical symptoms of CHF disease, how to communicate with the care recipient and healthcare team, and effective coping strategies. Nurses can provide evidence-based care to African American family caregivers of adult CHF patients based on recommendations from this systematic literature review. When African American family caregivers of adult CHF patient have the support, they need in their role, they can become better care givers to their sick relatives (Tsai, 2003). Providing better care by family caregivers can improve the quality of life for CHF patients and may eventually lead to reduction in the 30-day readmission rate (Wells et al., 2017). A healthier nation is a wealthier nation. This project supports the mission of Walden University to promote positive social change by improving the lives of African-American family caregivers of adult CHF patients, the well-being of their sick family members, and the health and worth of the African American community.

Summary

CHF is a debilitating disease with an increasing prevalence and far-reaching consequences (Benjamin et al., 2017). African Americans are impacted more and bear a disproportional burden of disease compared to European Americans (Thornton, & Hopp, 2011). Due to financial constraint, lack of insurance, and underinsurance, African American adults with CHF are more likely than their European American counterparts to end up at home and needing the help of a family member in management of the disease (Dickson et al., 2015). Family members who are caregivers to CHF patients are predisposed to many negative health outcomes (Tsai, 2003). The literature suggests that support can ameliorate the negative impact on family caregivers (Graspa et al., 2014; Mollaoglu et al., 2013; Tsai, 2003). However, African American family caregivers are unique in their caregiving role (Roth et al., 2015), but are underrepresented in research. Clinicians lack evidence-based strategies to care for them.

Due to lack of evidence-based recommendations and strategies, it is difficult for clinicians at the project site to offer culturally appropriate care to African American family caregivers of adults with CHF. Data from this systematic literature review provided evidence-based recommendations to facilitate best practices in the care of African American family caregivers of adults with CHF. Nurses will no longer rely on intuition and personal judgement when caring for the African American family caregiver of an adult CHF patient. In Section 2, I discuss the background, context of the project, and the concepts, models and theories used to complete this DNP project. I also explore the relevance of the project to nursing, the local background and context that prompted

the review of this problem, my role in the project execution, as well as the role of various project team members.

Section 2: Background and Context

Introduction

CHF is a debilitating chronic disease that leaves most adult sufferers needing help from a family caregiver. Family caregivers provide informal care that is substantial in scope, intensity, and duration (Reinhard et al., 2014). The caregiving role places family caregivers at risk for harm and they need and deserve protection and guidance. Thus, family caregivers are often seen as the “hidden” or “secondary” patients (National Alliance for Caregiving, 2015). The practice focus problem is that African American family caregivers of adults with CHF at the project site have little to no care given to them. At best, they are cared for with standard care that was developed for European American family caregivers of other chronic diseases. As such, they often lack the needed skills to navigate the formidable task of caregiving for a CHF patient, leading to compromised physical and psychological health (Durant et al., 2012; Thornton, & Hopp, 2011).

The literature review showed that African Americans have a highly complex culture, and members of this group are impacted differently by the caregiving role than other ethnic groups (Colvin et al., 2015; McCleary & Blain, 2013). They also have unique cultural beliefs that affect their needs (Durant et al, 2012; Thornton, & Hopp, 2011). For example, African Americans are culturally bound to care for a sick relative and consider placing a family member in a facility as taboo (Thornton, & Hopp, 2011). They preserve family harmony as a cultural imperative and find it difficult to say no to caregiving responsibilities (Pharr et al., 2014). African American family caregivers rely more on

spirituality as a coping mechanism compared to other ethnic groups (Dickson, McCarthy, & Katz, 2013). Richardson et al. (2017) noted, however, that a strong sense of cultural obligation for caregiving is associated with poorer psychological and physiological health.

CHF has a different trajectory compared to Alzheimer's disease, dementia, stroke, and cancer. Patients with CHF are readmitted to the hospital more often, and use more complex medical equipment than other chronic diseases (Cagle et al., 2017). Although CHF patients do not experience psychosis as do patients with Alzheimer's disease and dementia, or pain as with cancer patients (Honary et al., 2018), they have frequent symptom exacerbation such as edema and shortness of breath that incapacitate them, lead to frequent readmissions, and increase the burden of caring (Colvin et al., 2015). As such, family caregivers of adult CHF patients experience greater challenges in caregiving compared to caregivers of other chronic diseases (Hamilton, 2016). At a minimum, health care providers should recognize African American family caregivers of adult CHF patients as unique in their caregiving roles, direct them to available resources, and provide specific instructions regarding the care they are expected to provide.

The focused practice question for this DNP project was as follows: What evidence-based interventions are available to African American family caregivers of adults with CHF to support them in their role? The purpose of this project was to conduct a systematic literature review to appraise high-quality research to identify, analyze, and synthesize the evidence-based practices and best recommendations for African American family caregivers of adults with CHF at the project site. In this section, I describe the

theories, models, and concepts that guided this systematic literature review. I also define the terms as they are used in the project. Finally, I discuss the importance of this doctoral project to nursing practice, its local background, my role in the project, and the context of the problem as it relates to the project site.

Concepts, Models, and Theories

JBIM-SR

The JBIM-SR method guided this project (Pearson et al., 2005). The JBIM-SR process involves steps that guide the review process to minimize bias and errors inherent in systematic reviews. Using this model helped in extracting evidence-based practices for developing quality care. The research question was applied in the search strategy and guided the identification of relevant research data to extract, appraise, and synthesize. The evidence-based recommendations garnered from this project were subjected to the Joanna Briggs Institute (JBI), Grade of Recommendations, and levels of evidence for effectiveness (2014).

A grade of A shows that the desirable effects of the intervention clearly outweigh the undesirable effects; there is evidence of adequate quality support for the use of the intervention; there is a benefit or no impact on resources and the intervention took into account patient's values, preferences, and experience. A grade of A signifies a strong recommendation for the health management strategy (JBI, 2014). Grade B means that it is not clear if desirable effects of the intervention outweigh the undesirable effects; there are no high evidence supporting the use of the intervention; there could be minimal impact on resource use; and the values, preferences and experience of the patient may not

have been taken into consideration. A grade of B indicates a weak recommendation for the intervention or strategies (JBI, 2014).

The JBI Grades of Recommendations also uses the Feasible, Appropriate, Meaningful, and Effective [FAME] scale (Pearson et al., 2005) to determine the wording of a recommendation. The FAME scale weighs every intervention in terms of feasibility, appropriateness, meaningfulness, and effectiveness. Using the FAME scale, this systematic literature review extracted strategies and recommendations that will be feasible, appropriate, meaningful, and effective for delivering and improving care for African American family caregivers of adult CHF patients (Jordan et al., 2016). As noted by Steven (2013) evidence-based practice holds great promise for improving care, and increases the likelihood for producing the intended health outcome. The level of evidence for effectiveness, the Grade of Recommendations, and the FAME scale will be shown in the Appendix B and C

Theory of Caregiver Stress

This project was informed by the theory of caregiver stress proposed by Tsai (2003). The theory of caregiver stress is a middle-range theory adapted from Sister Callista Roy's Adaptation Model. Within the context of the theory, individuals are assumed to be adaptive systems that behave in certain ways when exposed to environmental stimuli, such as caregiving (Tsai, 2003). The theory proposed that in the presence of external stimuli (input), family caregivers activate their coping mechanism (control process) to help them adapt (effectors and output; Tsai, 2003). Support for the

family caregiver provides a buffering effect for caregiving burden. The theory relies on four assumptions:

- caregivers respond to environmental changes;
- caregivers' perceptions determine how they respond to environmental stimuli;
- caregivers' adaptation to environmental stimuli is a function of their adaptation level;
- caregivers' effectors also serve as their output and is the result of chronic caregiving (Tsai, 2003).

The theory of caregiver stress has four interrelated conceptual components: (a) input (caregivers' objective burden, stressful life events, social support, social roles, race, values, beliefs, age, gender, and relationship), (b) control process (perceived caregiver stress, depression), (c) effectors (physiological role, self-concept, role function and interdependence) and (d) output (physical function, self-esteem/mastery, role enjoyment and marital satisfaction). The theory identifies three types of environmental stimuli: focal, contextual and residual (Tsai, 2003). These stimuli are constantly changing forces that exert influences on human behavior. According to Tsai (2003) caregivers' objective burden is a focal stimulus and is the most important stimulus that affects perceived caregiver stress. Stimuli can impact an individual's behavior through coping mechanisms; thus, an individual's response is the function of environmental stimuli and his or her adaptation level. The resulting behavior is from the available control process such as coping and or depression.

The theory proposed that there is a relationship among the four components, assuming other factors are held constant. Environmental stimuli such as caregiver burden (focal stimulus); social support, stressful life events and social roles (contextual stimuli) and age, race, and gender (residual stimuli) produce adaptation responses in the four adaptive modes through perceived caregiver stress. Thus, in the presence of external stimuli, caregivers activate their coping mechanism to help them adapt. Caregivers' burden refers to the pressure of the caregiving role as a result of resources needed and can lead to perceived stress (Tsai, 2003). A high perceived caregiver burden results in ineffective response of low levels of physical function, self-esteem/mastery, role enjoyment and marital satisfaction (Tsai, 2003). Social support, and psychoeducational interventions reduce the caregiver's perceived caregiver burden by changing the perception of burden; social roles moderate the effect of the objective burden on perceived caregiver stress (Graspa et al., 2014; Tsai, 2003). Race, age, gender, and relationship with the care recipient influence perceived caregiver stress (Tsai, 2003). Thus, when the family caregivers perceive that they have an adequate support system and believe that their essential social needs are met, they experience improvement in their caregiving capabilities, and quality of life (Tsai, 2003).

To ascertain the appropriateness of the framework, there should be assessment of its clarity and consistency (Groves, Burns, & Gray, 2013). Numerous researchers have used the caregiver stress theory as a theoretical framework for research and practices (Amaya, Davis, & Fermano, 2014; Corà, Partinico, Munafò, & Palomba, 2012; Lee, DeDios, Simonette, & Lee, 2013; Tsai, & Pai, 2016; Hu et al., 2016). The caregiver stress

theory has been empirically tested using a data analysis technique proposed by Fawcett and Garity (2009). Caregiver stress theory is significant because it focuses on the life of family caregivers and the stress of caring for a relative with chronic illness. Family caregiving for a chronic illness is a condition that affects a large number of people and has great impact on their quality of life. A theory is significant if it is useful and extend knowledge (Fawcett & Garity, 2009).

Caregiver stress theory has internal consistency as it links its concepts to one another, is reasonable, has clearly identified and defined concepts, and is always consistent. Furthermore, caregiver stress theory is *parsimonious* as it has few concepts and propositions. According to Walker and Avant (2011) a parsimonious theory can concisely explain a complex phenomenon without losing the content, structure and completeness of the theory. Because caregiver stress theory proposed by Tsai (2003) is testable, significant, has internal validity, and is parsimonious, it is the best theoretical framework for this project. Nurses are at the forefront of using interventions to optimize mental and physical health of family caregivers. Adequate knowledge and understanding of the concepts of caregiver stress will help nurses utilize the theoretical framework to develop new interventions that will help caregivers cope with consequences they face as a result of their role (Llanque, Savage, Roseburg, Honor's & Caserta, 2016).

Definition of Terms

The terms found in this project are defined below.

Activities of daily living: Activities essential to meet the daily basic needs of an individual, such as bathing, grooming, feeding, dressing, toileting, mobility (Family caregiver Alliance, 2013).

Adult: Persons between the age of 18 and 64 (Kaizer, 2017).

African American: According to the United States Census Bureau (2012), persons having origins in any of the Black racial groups of Africa.

Caregiver burden: These are the pressure experienced by family caregivers due to the caregiving role. Caregiver burden can be objective, for example time spent in caregiving, gender, ethnicity, and finances; or subjective such as feeling of frustration, and stress. Subjective care burden can be changed easily through support (Karakurt et al., 2018).

Caregiver stress: Psychological appraisal of the caregiving experience that can manifest as anxiety, worry, depression, sleep impairment, unhealthy behaviors and loneliness (Bevans, & Sternberg, 2012).

European American: Persons of European, Middle Eastern, and North African descent (U.S Census Bureau, 2012).

Congestive heart failure: CHF is a chronic progressive illness that affect the pumping power of the heart muscles resulting in the inability of the heart to adequately supply for the body's metabolic demands, as well as allowing fluids to back up into the lungs and tissues; leading to symptoms such as edema, fatigue, and shortness of breath (Heart Failure Society of America, 2017).

Culturally sensitive care: Care that reflects “the ability to be appropriately responsive to the attitudes, feelings, or circumstances of groups of people that share a common and distinctive racial, national, religious, linguistic, or cultural heritage” (Department of Health and Human Services, Office of Minority Health, 2001, p. 131).

Family care giver: A spouse, family member, neighbor, or community member who cares for an individual who is unable to care for him/her self due to acute or chronic illness without financial compensation (Family Caregiver Alliance, 2015).

Health- related quality of life: An individual’s or a group’s perceived physical and mental health over time (Center for Disease Control and Prevention, 2017).

Instrumental activities of daily living: Activities that enhance the independent living of the individual such as balancing bank account, grocery shopping, doctor’s appointment, medication pick up from pharmacy, ensuring medication adherence, Cooking, and promotion of healthy living (Clark, 2012).

Intervention: A health intervention is an act performed for, with or on behalf of a person or population whose purpose is to assess, improve, maintain, promote or modify health, functioning or health conditions (World Health Organization, 2018).

JBIM- systematic review: A framework of literature review that compares current practices with old practices from literature to determine the best practice (Bennett, & Porche, 2017).

Systematic review: An exhaustive and rigorous analysis of all available literature on a topic of interest (Higgins, & Green, 2011), that results in a judgement of the effectiveness or otherwise of a particular practice (Pearson et al., 2005).

Project Relevance to Nursing Practice

A Brief History of the Broader Problem in Nursing Practice

There are limited interventions that are culturally tailored to care for the African American family caregiver of adult with CHF (Richardson et al., 2017). Thus, African American family caregivers of adult CHF patients and their sick relatives are exposed to more harm and negative consequences of the caregiving role compared to the European American population (Rowland, & Isaac-Savage, 2014). There are also no practice guideline or specific recommendations developed for the care of this population (Hamilton, 2016).

There is an expectation for health care practitioners to provide culturally sensitive care as an evidence-based imperative (Davidson et al., 2013). Evidence-based practice facilitates nursing decision- making (Jordan et al., 2016). The IOM recognizes evidence-based practice as a unique vehicle for knowledge translation (2012). Standardizing care for African American family caregivers of adult CHF patients can limit the unpredictable outcomes associated with variation in care practices (Aitken et al., 2015). Nurses can adopt the recommendations from this project to expand and gain new knowledge in the care of African American family caregiver of adult CHF patients. Other health care providers can also use the recommendation from this project to offer culturally and cognitively sensitive care to African American family caregivers of adults with CHF. The recommendations and evidence-based strategies garnered from this systematic literature review have the potential of enhancing nursing knowledge, changing clinical practices, and supporting providers caring for the African American family caregivers of adult with

CHF. Thus, through the recommendations from this systematic literature review, nurses can transition from intuition-based to evidence-based practices in the care of African American family caregivers of adult CHF patients.

Overview of the Literature

Evidence-based interventions for family caregivers is supported by literature. There are two categories of services provided by the family caregiver, thus activities of daily living (ADLs) and instrumental activities of daily living (IADLs). ADLs comprises such activities as bathing, feeding, grooming, dressing, and providing mobility, while IADLs are those activities that assist the care recipient to live as independently as possible such as bill paying, grocery shopping, banking, picking up medication, medication assistance, and providing transportation to doctor's appointments (Hamilton, 2016). Interventions can support the family caregiver directly by reducing potential injury and harm, distress, care burden, and overall negative influence on well-being or by enhancing their competencies, capabilities, and sense of control as caregivers (Reinhard et al., 2014). Other interventions target problem-solving skills, help with navigating the service delivery system, and linking caregivers to available resources (Graspa et al., 2014). Given the significant role of family caregivers, their needs should be assessed and addressed (Heo, 2014). This assessment is critical to limit harm to family caregivers and their sick relatives (Gary et al., 2018).

Lokensgard (2015) conducted a systematic literature review to investigate the effective interventions for African American and Hispanic Alzheimer's disease caregivers. The researcher analyzed and synthesized twelve articles that met the inclusion

criteria. The reviewer found three categories of interventions geared toward African American and Hispanic caregivers: In-home programs, Cognitive Behavior Therapy focused small groups, and support groups. The researcher found that interventions demonstrated an overall improvement in depression, diminished sense of burden, and other measures of healthy caregiver coping (Lokensgard, 2015). The study also revealed that majority of the interventions demonstrated little differences between racial or ethnic groups. The researcher concluded that cultural tailoring of interventions is advantageous to creating effective Alzheimer's disease caregiver interventions. The researcher recommended that practitioners should act with cultural sensitivity, curiosity, and responsiveness, as a means for effective cross-cultural interventions (Lokensgard, 2015). In a study by Agren et al. (2012), an integrated dyad care program with education and psychosocial support for adult CHF patients and their family caregivers resulted in increased perceived control, as well as reduced stress for the patient and their caregiver.

Piamjariyaku et al. (2015) conducted a mixed method designed coaching program with stratification and random assignment of family caregiver and heart failure patient dyad ($n = 20$). The researcher's objectives were to test if a family heart failure intervention adapted to the cultural needs of the African American family caregivers could reduce patient's heart failure related rehospitalization and improve family caregiver outcomes. The study also calculated the effect size on caregivers' outcomes and evaluated the family heart failure care. The study used descriptive univariate parametric /nonparametric, and post -hoc analysis to analyze data. The researchers determined that at six months, compared to standard care, the intervention group had significantly fewer

heart failure rehospitalization; while family caregiver confidence and social support scores were significantly higher. Family caregivers in the intervention group reported lower depression and rated the intervention as helpful. The authors concluded that culturally tailored interventions targeting African American family caregivers of CHF patients was associated with fewer heart failure related readmission, and improved family caregiver outcomes (Piamjariyaku et al., 2015).

Another study was conducted by Cothran, Paun, and Barnes (2017) to examine the African American Alzheimer's disease or other dementia diseases (ADRD) family caregivers' perceptions of the caregiving experience and self-care. The researchers conducted a 90-minute semi-structural individual interview with African American family caregiver of ADRD patients ($n = 24$) and found considerable physical and mental health issues impacting ADRD African American family caregivers. They concluded that further research is needed to inform the future design and implementation of a culturally tailored intervention for African American family caregivers of ADRD patients.

Samson, Monica, and Dye (2016) conducted a qualitative focus group study on African American family caregivers ($n = 32$) of adults with dementia to explore how issues of race and culture maybe incorporated into a culturally sensitive intervention for African American dementia family caregivers. The researchers found that African American caregivers display unique patterns of symptomology and responses to interventions designed to promote well-being. The key focus of the study was navigating care, the tradition of family care, and culturally appropriate care. The researchers concluded that intervention for African American caregivers should focus on developing

skills and knowledge for care giving, promote self-care, and reflect on African American family caregiver as a resource for care.

Durant et al. (2012) studied the community health advisors' observation on the role of social support in the lives of African American family caregivers. The subjects in this study were community health advisors ($n = 15$), working within African American communities in Birmingham, Alabama. The researchers used a semi-structured interview to obtain qualitative data. The researchers found that African American CHF patients and their family caregivers face challenges and community health workers can ameliorate challenges with social support. The conclusion of the study was that community health workers with experience in how to provide social support can inform a framework for a lay support intervention among African Americans suffering from heart failure and their family caregivers (Durant et al., 2012).

Thornton and Hopp (2011) studied the experiences of African American daughters caring for parents with heart failure. In the study, adult daughter caregivers ($n = 7$) completed an in-depth qualitative interview. The researchers used a phenomenological approach to analyze data and found the presence of socio-emotional stressors, distrust of health system, and relevant coping methods of spirituality, valuing of role, taking charge, and coordinating care with siblings (Thornton & Hopp, 2011). The authors concluded that health care workers can play the critical role of supporting African American family caregivers of adult CHF patient by helping them to cope with burden inherent in their role, connecting them with culturally responsive services, and enhancing the communication between families and health care providers (Thornton & Hopp, 2011).

Richardson et al. (2017) used an ethnocultural approach to explore how cultural factors influenced ethnically diverse dementia caregivers' experiences, and use of services. The researchers completed a modified thematic analysis of in-depth interview with caregivers ($n = 15$), from three minority groups: African American, Hispanic, and South Asia. The researchers found that caregiver stress was pervasive across all subgroups; but there were significant differences in the knowledge, language barriers, religion and spirituality, and cultural differences in attitudes about caring, and formal use of services (Richardson et al., 2017). The researchers recommended a two-pronged intervention model for minorities. Thus, a generic intervention to reduce caregiver stress, and a culturally targeted intervention tailored to the language, food preferences, religion practices, gender norms, and other values to more successfully support minority caregivers (Richardson et al., 2017).

Evidence to Address the Gap in Practice

Literature review showed that the current body of knowledge regarding the care of family caregivers has been derived mostly from European American family caregivers of patients with stroke, Alzheimer's disease, dementia, and cancer and has failed to provide the information needed to support African American family caregivers of adult CHF patients (Graham-Phillips et al., 2016; Hamilton, 2016; Lahaie et al., 2012; Thornton & Hopp, 2011). Given that African American family caregivers of adults with CHF are unique in their caregiving experience, are impacted differently by the role, and have a distinct symptomology and response to intervention (Dilworth-Anderson, & Gitlin, 2016), it is imperative to culturally tailor interventions geared toward them. This

project was a systematic literature review that endeavored to synthesize evidence-based recommendations to close the gap in nursing practice.

Local Background and Context

The American Occupational Therapy Association (AOTA) defines evidence-based practice (EBP) as “the integration of critically appraised research results with the clinical expertise, and the client’s preferences, beliefs and values” (n.d., para. 1). Thus, evidence-based care involves the offering of culturally sensitive care. In the project site, African American family caregivers of adult CHF patients are completely ignored and not seen as integral part of health provider team. When nurses attempt to assess and provide care to this population, the available modality of care is the same as those used for family caregiver of other ethnicity and diseases (Thornton & Hopp, 2011). This is problematic. There is a need to adopt evidence-based recommendations in the care of African American family caregivers of adult CHF patients to support the use of available best practice (Stevens, 2013).

Evidence to Justify Project Problem

Developing recommendations and strategies targeted to African American family caregivers is necessary to offer culturally tailored care. African Americans are a culturally distinct group of people bound by a unifying and functional system of norms, traditions, values and beliefs (Pharr et al., 2014). Due to their highly complex and diverse culture, African American family caregivers of adults with CHF are culturally identifiable entity and have a unique symptomology and response to intervention (Roth et al., 2015). Understanding the core elements of the African American culture and tailoring

programs to suit their cultural beliefs and values can improve their care giving capabilities, decrease distrust of healthcare providers, and help reduce caregiver stress and burden (Davidson et al., 2013). However, the literature suggests that African American family caregivers of adult with CHF are routinely ignored in studies, hence a need for a high-quality systematic literature review to explore available evidence-based recommendations and strategies for the care of African American family caregivers of adult with CHF.

Institutional Context

African American family caregivers of adult CHF patients at the project site receive care based on research conducted with European American population of other chronic diseases such as cancer, stroke, dementia, and Alzheimer's disease (Camak, 2015; Hamilton, 2016). It is not clear if the results of research completed with European American family caregivers of other diseases can be extrapolated to the African American family caregiver of adults with CHF. Due to the differences in the trajectory of CHF disease compared to other chronic diseases, and the distinct cultural heritage, socioeconomic status, and low educational status of the African American caregiver, it will be safe to assume that African American family caregivers of adult CHF patients will require a distinct set of interventions. Any intervention targeting the African American family caregivers of adult CHF patients should be tailored to account for fundamental disease and cultural differences.

Thus, considering the sporadic trajectory of CHF disease, complexity of the African American cultures, and their unique needs as family caregivers, it is imperative

to conduct a systematic review of interventions that targeted African American family caregivers of CHF adults. Recommendations and strategies from the systematic review will be used to develop educational materials for nurses and patients; and can be disseminated throughout the regional hospital system to help caregivers offer a culturally sensitive care to the African American family caregivers of adults with CHF

Role of the DNP Student

As a DNP student, I completed a systematic review using the JBIM-SR protocol to identify, analyze, and synthesize the best recommendations/intervention, and strategies available to African American family caregivers of adults with CHF. The project was carried out to fulfil my DNP program requirement, and to garner information that can support evidence-based, culturally tailored care for African American family caregivers of adult CHF patients. My professional role in the project was to complete a systematic literature review of recommendations and strategies available to African American family caregivers of adult CHF patient. Information collated from this project can ensure that clinicians have evidence-based recommendations needed to offer culturally sensitive care to African American family caregivers of adults CHF patients.

Motivation for Completing the Project

As a nurse, I have always been interested in the family caregivers and ways to improve outcome for them. I was motivated to complete this project to explore interventions that can improve the well-being of African American family caregivers of adults with CHF. The African American family caregivers of adults with CHF need a culturally tailored intervention to assist them in caring for their sick relative but are rarely

included in studies. This project can expose the lack of research with this population and can ignite the interest of researchers to complete studies with the African American family caregivers of CHF patients. I am also excited to complete the project as it signals the completion of my doctorate degree.

Potential Bias

The robust protocol of JBIM-SR that was used in this project will provide the strongest available evidence to support a clinical practice change. To eliminate potential bias, a second reviewer completed an independent literature search and reviewed the extracted evidence-based recommendations and strategies for African American family caregivers of adults with CHF. DNP project chairman and committee acted as overseers for the project.

Role of the Project Team

The project team included the DNP project leader (student), a secondary reviewer, nurses, unit managers and the director of nursing at the project site. The DNP project was presented to the team at the project site and the team were given the opportunity for feedback and to share their expertise and insight regarding the project. Also, I will use the team to disseminate the project findings, and to facilitate implementation at the project site.

Team Member Expertise and Contextual Insight

As the DNP project leader, my expertise and contextual insight will be derived from working in the cardiac unit of an acute care hospital for more than ten years. I am also a practicing nurse practitioner in an underserved regional hospital with large African

American population. During my work, I witnessed firsthand the experiences of African American family caregivers of adult CHF patients. I noticed that African American family caregivers of adult CHF patients seem eager to help their loved ones, but are frustrated due to lack of support from practitioners. Due to lack of support, African American family caregivers of CHF patients are at a loss of how to care for their sick relatives.

African American adult CHF patients are more likely than European Americans to be readmitted within 30 days for heart failure related symptoms (Muntner et al., 2017). Noticing the cultural complexity, unique caregiver needs and frustration experienced by African American family caregivers of adult CHF patients at the project site, I wondered if anything could be done differently to help them. Hence, this systematic review to explore interventions geared towards African American caregivers of adults with CHF. Although this project took part in my health care organization, it has no relationship to my current job responsibilities.

The second reviewer was a DNP prepared nurse practitioner with nine years of clinical experience in the primary care setting. The director of nursing at the project site has been in the position for more than 20 years. She has served in various organizational evidence-based committees. Committee chairwoman, and members will be professors at Walden University, with varied experience in the nursing field.

Team Members' Responsibilities and Timeline

After obtaining IRB approval, the systematic literature review was conducted using the JBIM-SR process (Pearson et al., 2005). The literature was searched, studies

reviewed, analyzed, synthesized and recommendations were made based on the findings. To prevent bias, a DNP prepared nurse served as a second reviewer and replicated the search using same terms, electronic databases, and inclusion and exclusion criteria. Additionally, the second reviewer verified the resulting literatures. Committee chair and members reviewed the work and made various suggestions for improvement before completion.

Summary

African American family caregivers of adults with CHF have unique needs as caregivers and need evidence-based culturally tailored care to improve quality, safety and outcome (Davidson et al., 2013). It becomes essential to appraise high quality evidence-based researches to explore best practices in the care of African American family caregiver of adult CHF patient to inform clinical practice changes. Systematic literature reviews of high- quality quantitative and qualitative studies provided the best rigorous evaluation of evidence needed to identify current practices. Information from this project can inform clinical practice change, and support the development of evidence-based recommendations and strategies for African American family caregivers of adult CHF patients.

In Section 3, I discuss the collection and analysis of evidence, sources of evidence, published outcomes and research, and analysis and synthesis of the project.

Section 3: Collection and Analysis of Evidence

Introduction

Offering the evidence-based care deserved by African American family caregivers of adult CHF patients is challenging due to limited published research targeting them. This DNP project was intended to collate, analyze, and synthesize high-quality evidence that can be adopted as recommendations for the care of African American family caregivers of adult CHF patients. The JBIM-SR model (Pearson et al., 2005) was used to guide the systematic literature review. The JBIM-SR model provides a clear and objective guideline which limits errors and bias inherent in systematic literature reviews (Jordan et al., 2016). In this section, I discuss the purpose and method alignment of the project, sources of evidence, and published outcomes and research. This section also includes the search strategies used in the systematic review, the analysis and synthesis of data, data integrity, and data analysis. The section concludes with a summary and a preview of Section 4.

Practice-Focused Question

Researchers have consistently noted that culturally tailored care will optimize the well-being of African American family caregivers and their relatives with CHF (Agency for Healthcare Research and Quality, 2015; Gary et al., 2018; Reinhard et al., 2014; Richardson et al., 2017). Yet African American family caregivers of adults with CHF at the project site are cared for based on research conducted with European American family caregivers of adults with cancer, stroke, dementia, and Alzheimer's disease (Graham-Phillips et al., 2016; Hamilton, 2016; Lahaie et al., 2012; Thornton & Hopp,

2011). It has not yet been ascertained whether evidence gathered from research on European American participants is appropriate to be used on their African American counterparts. The practice-focused question for this project was as follows: What evidence-based interventions are available to African American family caregivers of adults with CHF to support them in their role? I developed this question to guide the exploration of the available evidence-based recommendations for African American family caregivers of adults with CHF.

Project Purpose and Method Alignment

The purpose of this DNP project was to identify the best evidence needed to provide culturally tailored and cognitively appropriate care to African American family caregivers of adults with CHF. For this project, I conducted a comprehensive systematic literature review to synthesize the best evidence available to culturally tailor care to African American family caregivers of CHF adult patients. The systematic literature review included quantitative and qualitative studies, relevant to the practice question, to ascertain best practice recommendations for the African American family caregivers of adults with CHF. Jordan et al. (2016) noted that systematic reviews provide the best rigorous evaluation of evidence to inform change in clinical practice. Also, systematic reviews are characterized as the central link between research and clinical decision making (Institute of Medicine, 2012).

A systematic literature review was the best method to collect and analyze evidence for this project because it is considered a rigorous way to extract evidence in an unbiased manner by relying on the use of an objective, transparent approach (Mallett,

Hagen-Zanker, Slater, & Duvendack, 2012). The unmanageable plethora of information on a subject often leaves providers and policy makers inundated (IOM, 2012). Using a systematic literature review, scientific findings can be evaluated to determine their consistency, and generalizability across setting, treatment variation, and population; and to determine if findings have significant variability by subsets (Mallett et al., 2012). Thus, a systematic literature review can provide data needed for clinical decision -making and helps to integrate evidence efficiently into practice.

Systematic literature reviews adopt a broad search strategy using established uniform inclusion and exclusion criteria and a framework that forces reviewers to include all studies in the subject area, hence eliminating bias and improving reliability and accuracy of conclusions (IOM, 2012). The practice -focused question is set at the beginning of a systematic literature review, thus ensuring the review process is tightly focused and produces a clearer and objective answer to the research question. A systematic literature review focuses strongly on impact, validity, evidence, and causality and is effective for estimating the robustness of any evidence. The process of systematically reviewing literature allows researchers to engage more critically with studies, giving them the opportunity to be consistent in their prioritization of empirical evidence above their preconceived knowledge (Mallett et al, 2012). Evidence-based recommendations and strategies gathered from this systematic literature review will provide answers to the practice focused question, and can inform change in clinical practice in the care of African American family caregivers of adult CHF patients.

Sources of Evidence

The sources of evidence for this project included searching through the databases available through the Walden library and, such as Cochrane Library, Joanna Briggs Institute Evidence- Based Practice database, CINAHL, Clinical Trial.gov, Medline, PsycINFO, and PubMed for peer -reviewed research literature. Additionally, official websites such as the American Heart Association, and Heart Failure Society of America were accessed for resources. The practice-focused question guided the inclusion and exclusion criteria, as well as the key words and phrases for the search. I used the JBIM-SR model (Pearson et al., 2005) as the guide to searching, extracting, and evaluating data relevant to the research question. The article selection procedure followed the PRISMA flowchart (Moher et al., 2009). I organized the synthesized and analyzed evidence using a literature review matrix (see Appendix E).

Published Outcomes and Research

Evidence-based recommendations and strategies needed for the care of African American family caregiver of adult CHF patients will be extracted from published outcomes and research articles within this systematic literature review. Practices based on evidence has scientific merit and can increase the chances of improving quality of care, as well as providing predictable and reliable patient outcomes (Stevens, 2013).

Relationship of the Evidence to the Purpose

The purpose of the systematic literature review was to evaluate and synthesize the best available evidence that can be developed into recommendations and strategies for the care of African American family caregiver of adult CHF patient. Health care practitioners

have used various strategies and recommendations in the care of this population. A systematic literature review provided an exhaustive evaluation of available literature to validate clinical practices.

Evidence to Address the Practice-Focused Question

A strategy search of the electronic databases including CINAHL, Clinical Trial.gov, Medline, PubMed, PsycINFO, Cochrane database of systematic review, and Joanna Briggs Institute systematic review, was completed. The inclusion criteria were as follows: peer-reviewed full text articles, published between January 1, 2008 and December 31, 2018, written in English language and studies with more than 90% African American family caregivers of adult CHF patient participants. Research articles that include CHF caregivers in aggregate of other chronic diseases such as stroke, Alzheimer's diseases, dementia, and cancer will be excluded. Literatures not meeting the inclusion criteria will be excluded. The research types included systematic reviews, quantitative studies, qualitative studies, random controlled trials (RCT's), clinical trials, and clinical guidelines.

Literature Search Strategy

Online databases that were used include CINAHL, Clinical Trial.gov, Medline, PubMed, PsycINFO, Cochrane Database of Systematic Review, and Joanna Briggs Institute Evidence- Based Practice database. Additional data were obtained from journals such as the American Heart Association journal, Circulation, journal of cardiac failure, and journal of American College of Cardiology. Data were also extracted from official

websites of the American Heart Association, National Caregivers Alliance, and Heart Failure Society of America.

The key terms that were used include *African American* or *Black* or *Negro*, or *Afro-American* and *family caregiver* or *informal caregiver* or *relatives* or *neighbors* or *friend* and *intervention* or *support* and *CHF* or *heart failure*, or *chronic heart failure*.

The Scope of the Review

The purpose of this systematic literature review was to explore the relevant evidence as it relates to the care of African American family caregiver of adult CHF patients. The search will be limited to peer-reviewed articles between 2008 and 2018.

The articles were included if the authors:

1. Addressed intervention for the African American caregiver of adult CHF patients
2. The articles are relevant to the practice question.
3. They are either full text or not

Articles were excluded if:

1. They do not include more than 90% African American Family Caregiver of adult CHF participants.
2. If they include African American Family caregiver of adult CHF patient in aggregate of other chronic diseases such as cancer, stroke, dementia, or Alzheimer's disease.
3. They are published before 2008.

Search Exhaustive and Comprehensive

To ensure that search was exhaustive, I used multiple search terms and phrase combinations relevant to the practice-focused question. I read the articles selected in full to determine inclusion or exclusion based on established selection criteria. Also, I reviewed all abstracts, article references to ensure all relevant studies were included.

Institutional Review Board

This project was a systematic literature review and did not have issues with protection of human rights. The data were from approved public databases. However, before execution of the project, a full approval was obtained from the Walden University Institutional Review Board (IRB) The approval number is 05-08-19-0381639.

Analysis and Synthesis

I used the JBIM-SR model to conduct a comprehensive search of the literature for articles related to the problem question. This systematic literature review considered both qualitative and quantitative studies that provide intervention to African American family caregiver of an adult CHF patient. The article selection procedure followed the PRISMA flowchart (Moher et al., 2009). Prior to inclusion in the review, quantitative articles were subjected to methodological validity assessment using the standardized critical appraisal instrument from Joanna Briggs Institute Meta-Analysis of Statistics and Review Instrument (JBI-MASARI) while the qualitative studies were assessed with the JBI-Qualitative Assessment and Review Instrument (JBI-QARI; Jordan et al., 2016).

I subjected selected articles to the JBI Grades of Recommendation and FAME scale to ascertain the feasibility, appropriateness, meaningfulness and effectiveness of the

recommendations (Jordan et al., 2016). Data from quantitative studies were extracted using the JBI-MASARI extraction tool and JBI QARI data extraction tool was used to extract data from qualitative studies. I presented extracted data in a literature review matrix. All systems used for recording, tracking, organizing, and analyzing the evidence are presented in the appendix.

Data Systems and Procedures

Systematic literature reviews are criticized for high dependency on reductionist and standardized framework that does not capture the individual variability and effect of contextual influence on interventions (Mallett et al., 2012). This systematic review included qualitative studies to help capture ethnic differences in family caregiver experiences. Studies identifying interventions and recommendation for African American family caregivers of adult with CHF will be subjected to the JBI Grade of Recommendations. Extracted data will be appraised and synthesized into evidence and will be recommended for implementation in clinical settings.

Data Integrity

The project used public and secondary data bases to access research articles. There are no human subjects use in the project. The systematic literature review protocol was reviewed and approved by the Walden University Institutional Review Board prior to searching the databases.

Data Analysis

Extracted data were analyzed using the [JBI] (2014) grading chart. In this grading chart, Grade A represents strong recommendations with high quality evidence and likely

highly effective outcome. Grade B are weak recommendations for a health management strategy because desirable and undesirable effects are not clearly distinguished. The (FAME) scale (JBI, 2016) was used to determine if data provide useful, effective, and meaningful evidence that can inform change in practice in the care of African American family caregivers of adult with CHF. Findings from this project were presented in narrative format.

Summary

A systematic literature review of evidenced-based peer reviewed articles provided data that was analyzed and synthesized into best evidence to inform change in clinical practice for the care of African American family caregivers of adults with CHF (Jordan et al., 2016). This project used the JBIM-SR model to extract, analyze, and synthesize data to find the best practice recommendations available to the African American family caregivers of adult with CHF and clinicians who care for them. Recommendations from this review has the potential of informing change in practice for the African American family caregiver of adult CHF patient.

In Section 4, I discuss the findings and recommendations of this project, the contribution of the doctoral project team, implications of the project and the strengths and limitations of the project.

Section 4: Findings and Recommendations

Introduction

African American family caregivers of adult CHF patients provide a substantial amount of care to their relatives and should be regarded as important co-providers of care (Foebel et al., 2012). Family caregivers contribute enormous economic value to the health care resources (Hopps et al., 2017). However, the literature reveals that African American family caregivers of adult CHF patients experience significant negative physical and psychological outcome due to their role and because little to no attention is paid to their needs (Graspa et al., 2014; Lorraine et al., 2018). Providing support for family caregivers has been shown to reduce caregiver stress, increase caregiving capabilities, and improve outcomes for both caregivers and the patient (Burke et al., 2014). According to the dictates of evidence-based care model, nursing should provide care within the context of the care recipient (Stevens, 2013). Disregard for the cultural and cognitive needs of African American family caregivers of adults with CHF is a source of increased caregiver burden and distress (Bevans & Sternberg, 2012; Hopps et al., 2017). Health care providers should understand the core elements of the African American culture and tailor interventions to suit their cultural beliefs and values (Davidson et al., 2013). Appraising high-quality, evidence-based studies will identify evidence-based best recommendations and strategies for the care of African American family caregiver of adult CHF patients.

For this project, I used citation chaining to help locate newer studies that are relevant to the practice question. Due to the paucity of research on the topic of review, I

changed the inclusion and exclusion criteria to include articles that were not full-text. I liaised with the university librarian to locate articles that were not full text, but relevant to the practice question. Finally, I made particular efforts to search dissertation and theses databases, such as Scholarworks and ProQuest, to locate items that were related to the practice question. The methodological standards for systematic literature reviews recommend extensive searching of the literature to reduce publication bias, reflect the totality of evidence on the practice problem, and produce accurate and valid estimates of the outcome (Balshem et al., 2013). However, Hartling et al. (2017) found that searching additional sources was associated with diminishing returns, and the impact of continuing search was insignificant.

I reviewed abstracts and article references and I read selected articles in full to determine if they met the specified inclusion/exclusion criteria. I obtained 117,793 articles from PubMed, 75 articles from CINAHL, 100 articles from Medline, 17 articles from Clinical Trial.gov, 14 articles from Scholarworks, four articles from Cochran Review, 34 articles from PsycINFO, and 41 articles from Joanna Briggs Institute's Evidence-Based Practice database of systematic reviews. Total articles ($n = 118078$) were identified through all searches. Duplicate records ($n = 163$) were removed. Titles of articles ($n = 117915$) were reviewed and articles ($n = 117880$) were excluded due to having no relevance to the practice question. The abstracts of articles ($n = 35$) were reviewed and articles ($n = 0$) were excluded. I read 35 articles in full and further excluded 34 articles because they were not interventions directed at the African American family caregivers of adult CHF patients (see Appendix D). The one study that met the inclusion

criteria for the systematic review was analyzed and synthesized and the findings are presented (see Appendix E).

Findings

The one study that met the inclusion criteria was analyzed and synthesized for the completion of the systematic literature review. I used the JBIM-SR grading chart (see Appendix B) and the levels of evidence for effectiveness (see Appendix C) to grade the quality of the evidence. Grade A represents strong recommendations with high quality evidence and likely highly effective outcomes; Grade B are weak recommendations for a health management strategy because desirable and undesirable effects are not clearly distinguished (JBI, 2014). For this systematic literature review, evidence-based recommendation for African American family caregivers of adult CHF patients consisted of a telephone coaching of a culturally adapted educational materials called Family Heart Failure Care Intervention (FamHFcare; Piamjariyaku & Smith, 2014). The available evidence indicates that African American family caregivers of adult CHF patients will benefit from receiving culturally sensitive care in the community setting.

The FamHFcare intervention is a culture-specific telephone coaching intervention for African American CHF patients and their family caregivers led by nurses (Piamjariyakul & smith, 2014). It consists of information on CHF discharge instructions, standard care information, and 5 weeks of posthospitalization coaching on relevant CHF home care skills specific to African American family caregivers of adult CHF patients (see Appendix F). Coaching and teach-back strategies that require family caregivers to narrate what they understood to the coach were used during the sessions.

Piamjariyakul and Smith (2014) developed the FamHFcare tool from the result of a qualitative community based participatory study they conducted. The study participants included 40% of adult CHF patient and their African American family caregivers managing heart failure at home. In the study, the participants were asked to identify the culturally-specific preferences of African American families managing CHF at home (Piamjariyakul et al., 2012). The participants identified telephone coaching, multiple family members involved in caregiving, family support, spirituality, and reluctance to contact physicians as some culturally specific practices among African American family caregivers (Piamjariyakul et al., 2012). CHF home management standard guidelines from the Joint Commission and Hospital Accreditation (JCAHO) Heart Failure Core Measure Sets and national clinical guidelines for CHF home management were incorporated as part of the intervention (Piamjariyakul & Smith, 2014). Finally, a feasibility study was completed to test telephone coaching as an intervention with 20 family caregivers randomized to intervention and control group. The feasibility study showed that participants rated telephone coaching of FamHFcare as effective, and it cost about \$350 per patient to complete. Thus, the researchers concluded that telephone coaching of FamHFcare is helpful and feasible as an intervention (Piamjariyakul et al., 2013).

In the included article for this systematic literature review, Piamjariyakul et al (2015) tested the FamHFcare intervention on African American family caregivers of adult CHF patients and their sick relatives. The intervention strategies were adapted to the preferences, customs, traditions, diet tendencies, and social and community support resources specific to African American family caregivers of adult CHF patients

(Piamjariyakul et al., 2015). Using the telephone coaching intervention, African American adult CHF patients ($n = 20$) and their African American family caregivers ($n = 20$) were randomly assigned to the intervention or to the standard (usual) care group. The standard care group received care based on the JCAHO approved Heart Failure Core Measures Set which include assessing the patients' symptoms according to the New York Heart Association Classification, evaluating and documenting the left ventricular function of the patient within 12 months, prescribing of angiotensin-converting enzymes inhibitors and beta blockers for patients with ejection fraction less than 40% or documenting why the medications are not prescribed, and educating patients and families on activities, diet control, drug compliance, and follow-up (Zafar et al., 2016). The intervention group received the JCAHO approved Heart Failure Core Measure set and 5 weeks of adapted FamHFcure, a telephone coaching intervention led by nurses. Topics covered included motivating caregivers to be involved in medication adherence, fluid management, and salt restriction of the patient; developing daily management skills; coaching on how to manage caregiver stress, burden, and when to seek professional help; and preparing for emergencies and how to navigate sensitive end of life discussions (Piamjariyakul et al., 2015).

The objective of the Caregiver coaching program effect: Reducing heart failure patient rehospitalizations and improving caregiver outcomes among African Americans (Piamjariyakul et al., 2015) was to test whether the culturally sensitive telephone coaching intervention (FamHFcure) delivered to African American family caregivers of adult CHF patients and their sick relatives could reduce patients' heart failure related

rehospitalization, family caregiver burden and depression, increase family caregiver confidence, social support, and preparedness. The researchers also aimed to evaluate the effect size of caregiver outcomes; as well as evaluate the caregivers' and nurses' perceptions of the FamHFcare intervention (Piamjariyakul et al., 2015). The study was a mixed method design with stratification and randomization. Descriptive statistics were used to analyze data. The researchers found that at 6 months post intervention, the intervention group had a significant reduction in rehospitalization compared to the control group and African American family caregivers of adult CHF patients showed improvement on the confidence scale, had higher perceived social support, and had significantly lower depression and decreased burden of care. The caregivers also rated the FamHFcare telephone coaching as helpful (Piamjariyakul et al., 2015).

Data from this review supports the development of a culturally sensitive intervention for the care of African American family caregivers of adult CHF patients. There is a paucity of studies evaluating the needs of African American family caregivers of adult CHF patients. This finding is concerning as CHF is predominant in the Black community. Lack of studies for the care of African American family caregivers of adult CHF patients underscores the importance of family caregiver assessment and support in the African American community. As noted by Altman & Bland (as cited in Gewandter et al., 2017), absence of evidence is not evidence of absence. The findings of this project are aligned to the known fact that African Americans, CHF patients and minorities are mainly ignored in researches (Sullivan et al., 2018; National Academies of Sciences, Engineering, & Medicine, 2016). The evidence-based information obtained from this

systematic literature review can strengthen the demand for legislative mandates to protect African American family caregivers from the perils of the caregiving role.

Implications

According to Piamjariyakul et al. (2015), family caregivers are the most effective, but least utilized intervention in the management of CHF patients. Sherman et al (2014) noted that CHF rehospitalization is mostly related to poor medication management, excess intake of dietary sodium, and fluid overload; which could be avoided by involving and supporting the family caregivers. With the increasing prevalence of CHF among African American adults and the rising cost of informal caregiving for patients with CHF (Joo, Fang, Losby, & Wang, 2015), designing and implementing a culturally sensitive intervention that target African American family caregivers of adult CHF patients is imperative. Providing evidence-based recommendations for African American family caregivers of adult CHF patients will save healthcare resources, enhance caregiving capabilities, decrease caregiver burden and stress, improve patient outcome, and increase the quality of life of both the African American family caregiver, and their sick relative (Hopps et al., 2017).

Recommendations

Based on the limited evidence that supports the provision of cultural-specific interventions in the care of African American family caregivers of adult CHF patients, it is recommended that further high-quality research be completed with this population. Randomized Controlled trials (RCTs) of interventions such as psychoeducation, caregiver support groups, psychotherapy, respite, emotional cognitive therapy, telehealth, and

spiritual/religious coping (Cothran et al., 2017; Lokensgard, 2015; Richardson et al., 2017 ; Samson et al., 2016) that have shown positive results in the care of European American family caregivers of dementia, Alzheimer's disease, Cancer, and Stroke patients should be completed with the African American family caregivers of adult CHF patients to determine their effectiveness.

However, Jordan et al (2016) noted that, in the absence of further studies, results from poor quality studies and expert opinions can represent the best available evidence for a practice problem. Based on this systematic literature review, the best available intervention for African American family caregivers of adult CHF patients is the FamHFCare intervention (Piamjariyakul et al., 2015). Pending further studies with this population, it is suggested that FamHFCare intervention be adopted by health care organizations to care for African American family caregivers of adult CHF patients.

The recent spark of interest among federal policy makers to advance the cause of family caregivers is a welcomed development. The Recognize, Assist, Include, Support, and Engage (RAISE) Family Caregiver Act was recently signed into law by president Donald Trump and requires the department of Health and Human Services to come up with a plan to support those who care for family members with illness, disability or functional limitations (McKnight L., 2018; Potera, 2017). This review can provide evidence to gain support and funding for research with the African American family caregiver of the adult CHF patient.

Contributions of the Doctoral Project Team

The DNP protect team included the student, a second reviewer, and the nurses and management at the project site. The DNP student served as the project leader and drew up the project proposal. The DNP committee members approved the project proposal, which was subsequently presented to the Walden's IRB for approval. The second reviewer replicated the literature search using the same terms, inclusion and exclusion criteria and search engines. When the two reviewers disagreed on an article to include in the review, consensus was reached to either include or exclude the article. Data extractions and grading were completed with the JBI-SR tools and a literature review matrix was used in organizing and presenting data (see Appendix E).

Strengths and Limitations of the Project

The strength of this project is that recommendations were obtained through systematic literature review of available high-quality evidence. According to Pearson (2005), the results of well-designed research studies are more credible as evidence compared to anecdotes or personal opinion. Limitations of the project is that only one article provided recommendations for the care of the African American family caregiver of adult CHF patients. Sometimes, research does not always exist for every intervention, practice or population. According to Jordan et al (2016), when no research evidence exists, poor quality research or expert opinion can be seen to represent the best available evidence.

Summary and Conclusions

The available evidence suggests that culturally specific interventions are the best practice for the care of African American family caregivers of adult CHF patients.

Studies that focused on the intervention or recommendations for the African American family caregivers of adult CHF patients were limited in number, scope and quality. The sparsity of studies evaluating the needs of African American family caregivers of adult CHF patients is concerning. African American family caregivers of adult CHF patients have cultural differences that affect their caregiving roles. For example, they have a more positive appraisal of the caregiving role, greater spirituality or use of prayers, stronger belief in filial responsibilities, a higher value placed on extended family network, and a greater aversion to institutionalizing a sick relative compared to the European American population (Pharr et al., 2014; Sheet el al., 2014). Cultural tailoring of intervention for this ethnic group is essential and should address language, literacy, familism, need for advocacy, logistical barrier, and mistrust of the health care system (Piamjariyakul et al., 2015).

Systematic literature reviews of high-quality research provide the highest level of evidence and will most likely support the development of recommendations and strategies for the care of African American family caregivers of adult CHF patients. The best practice for the care of African American family caregiver of adult CHF patients based on this systematic review is the culturally sensitive intervention of telephone CHF home care coaching program (FamHFcure). Additional research is needed to identify best recommendations for African American family caregivers of adult CHF patients.

Section 5: Dissemination Plan

Introduction

The dissemination plan for this project is to encourage the management at the project site to adopt the FamHFcare intervention as the standard care modality for African American family caregivers of adult CHF patients. I have discussed the dissemination of the project with my preceptor, the director of nursing, who is willing to conduct a pilot study with a unit in the cardiac center. The project site can convert the recommendations into educational materials for nurses to use in the care of African American family caregivers of adult CHF patients. The recommendations can also be converted into audio/visual formats and distributed to African American family caregivers of adult CHF patients in barber shops, churches, and places with large gatherings of African Americans. The project will also be submitted for publication in journals, and to heart failure organization websites.

Analysis of Self

For this project, I acted as the project leader and served as a resource to other project team members. I have the professional ability to conduct a systematic literature review to synthesize the best evidence that can lead to changes in practice, policies, and protocols in the care of African American family caregivers of adult CHF patients. I view myself as a scholar and as an advocate for the family caregivers, especially those of the African American community that suffer various health, economic and social disparities (Dickson et al., 2015; Dionne-Odom et al., 2017; Durant et al., 2012; Lahaie et al., 2012; National Alliance on Caregiving, 2015).

The process of completing this DNP project was very challenging and lasted longer than I expected. The unexpected extended time contributed to additional financial constraint. It was helpful to have a template that detailed what to expect at every stage of the process. For the future, I plan on collaborating with legislators and leadership to garner support and funding for research with African American family caregivers of adult CHF patients.

Summary

This systematic literature review of high-quality research was able to synthesize evidence-based practices available for the care of African American family caregivers of adult CHF patients. Recommendations garnered through this project can be used to develop evidence-based care modalities and protocols to ensure adequate care of the population. The project added to nursing knowledge, and will allow nurses to utilize evidence-based practices while caring for African American family caregivers of adult CHF patients.

References

- Agency for Healthcare Research and Quality. (2015). Disparities in health care quality among racial and ethnic minority groups: Selected findings from the 2010 National Healthcare Quality and Disparities Reports. Retrieved from <http://www.ahrq.gov/qual/nhqdr10/nhqdrminority10>
- Agren, S., Evangelista, L. S., Hjelm, C., & Strömberg, A. (2012). Dyads affected by chronic heart failure: A randomized study evaluating effects of education and psychosocial support to patients with heart failure and their partners. *Journal of Cardiac Failure, 18*(5), 359–366. doi: 10.1016/j.cardfail.2012.01.014
- Aitken, L. M., Bucknall, T., Kent, B., Mitchell, M., Burmeister, E., & Keogh, S. (2015). Sedation protocols to reduce duration of mechanical ventilation in the ICU: A Cochrane systematic review. *Journal of Advanced Nursing, 72*(2), 261–272. doi:10.1111/jan.12843
- Akosile, C., Okoye, E., Nwankwo, M., & Mbada, C. (2011). Quality of life and its correlates in caregivers of stroke survivors from a Nigerian population. *Quality of Life Research, 20*(9), 1379–1384. doi:10.1007/s11136-011-9876-9
- Amaya, J., Davis, A., Femano, C. (2014) Review of the Caregiver Stress Theory to analyze stress among parents of infants in neonatal intensive care unit (NICU). Retrieved from <http://www.slideshare.net/ashbrink/caregiver-stress-37479903>
- American Association of Heart Failure (2017). What is heart failure? Retrieved from https://www.aahfn.org/mpage/what_is_hf

American Heart Association. (2014). Heart and stroke statistics—2014 update.

Retrieved from http://www.heart.org/HEARTORG/General/Heart-and-Stroke-Association-Statistics_UCM_319064_SubHomePage

American Occupational Therapy Association. (n.d.). Evidence-based practice & research.

Retrieved from <https://www.aota.org/Practice/Researchers.aspx>

Arundel, C., Sheriff, H., Bearden, D. M., Morgan, C. J., Heidenreich, P. A., Fonarow, G.

C.,...Ahmed, A. (2018). Discharge home health services referral and 30-day all-cause readmission in older adults with heart failure. *Archives of Medical Science*, 14(5), 995–1002. doi:10.5114/aoms.2018.77562

Balshem H., Stevens A., Ansari M., Norris S., Kansagara D., Shamliyan T., ...

Dickersin K. (2013). Finding grey literature evidence and assessing for outcome and analysis reporting biases when comparing medical interventions: AHRQ and the Effective health care program. Methods guide for comparative effectiveness reviews. Retrieved from <https://www.ncbi.nlm.nih.gov/pubmed/24404628>

Benjamin, E., Blaha, M., Chiuve, S., Cushman, M., Das, S., Deo, S., & Muntner, P.

(2017). Heart disease and stroke statistics-2017 update: A report from American Heart Association. *Circulation*, 135(1), e146-e603. doi:1.1161/CIR.0000000000000485

Bennett, M., & Porche, D. (2017). JBI database of systematic reviews and

implementation reports. *JBI Database of Systematic Reviews and*

Implementation Reports, 15(3), 584-585. doi:10.11124/jbisrir-2016-003335

- Berchick, E., Hood, E., & Barnett, J. (2018). Health insurance coverage in the United States: 2017. Retrieved from <https://www.census.gov/content/dam/Census/library/publications/2018/demo/p60-264.pdf>
- Bergethon, K., Ju, C., DeVore, A., Hardy, N., Fonarow, G., Yancy, C., ...Hernandez, A. (2016). Trends in 30-day readmission rates for patients hospitalized with heart failure: Findings from the get with the guidelines-heart failure registry. *Journal of Circulation of Heart Failure*, 9(6). doi:10.1161/circheartfailure.115.002594
- Bevans, M., & Sternberg, E. M. (2012). Caregiving burden, stress, and health effects among family caregivers of adult cancer patients. *Journal of American Medical Association*, 307(4), 398-403. doi:10.1001/jama.2012.29
- Buck, H.G., Zambroski, C.H., Garrison, C., & McMillan, S.C. (2013). Everything they were discussing, we were already doing: Hospice heart failure caregivers reflect on a palliative caregiving intervention. *Journal of Hospice and Palliative Nursing*, 15(4), 218-224. doi:10.1097/njh.0b013e3182777738
- Buck, H.G., Zambroski, C.H., & Hupcey, J.E. (2013). Assessing the response of patients and spousal partner caregivers to a new instrument measuring dyadic heart failure care type. *European Journal of Cardiovascular Nursing*, 12(2), 209-213. doi:10.1177/1474515112471479
- Burke, F., Jones, J., Ho, P., & Bekelman, D. (2014). Caregivers' perceived roles in caring for patients with heart failure: What do clinicians need to know? *Journal of Cardiology Failure*, 20(10), 731-738. doi: 10.1016/j.cardfail.2014.07.011

- Cagle, J. G., Bunting, M., Kelemen, A., Lee, J., Terry, D., & Harris, R. (2017). Psychosocial needs and interventions for heart failure patients and families receiving palliative care support: A systematic review. *Journal of Heart Failure Reviews*, 22(5), 565–580. doi:10.1007/s10741-017-9596-5
- Camak, D.J. (2015). Addressing the burden of stroke caregivers: A literature review. *Journal of Clinical Nursing*, 24(17-18), 2376-2382. doi:10.1111/jocn.12884
- Centers for Disease Control and Prevention (2000). Measuring healthy days: Population assessment of health-related quality of life. PsycEXTRA Dataset. doi:10.1037/e372122004-001
- Clark, A. L. (2012). Instrumental activities of daily living: More than just piano-playing? *European Journal of Heart Failure*, 14(6), 565- 566. doi:10.1093/eurjhf/hfs065
- Clark, A. M., Spaling, M., Harkness, K., Spiers, J., Strachan, P. H., Thompson, D. R., & Currie, K. (2014). Determinants of effective heart failure self-care: a systematic review of patients' and caregivers' perceptions. *Journal of British Cardiac Society*, 100(9), 716–721. doi:10.1136/heartjnl-2013-304852
- Colvin, M., Sweitzer, N. K., Albert, N. M., Krishnamani, R., Rich, M. W., Stough, W. G., ... Moore, S. (2015). Heart failure in non-Caucasians, women, and older adults: A white paper on special populations from the Heart Failure Society of America Guideline Committee. *Journal of Cardiac Failure*, 21(8), 674–693. doi: 10.1016/j.cardfail.2015.05.013

- Cothran, F., Paun, O., & Barnes, L. (2017). African American Alzheimer Disease or Related Dementia (ADRD) family caregiver's perceptions of caregiving and self-care. *Journal of Innovation in Aging, 1*(1), 188. doi:10.1093/geroni/igx004.718
- Corà, A., Partinico, M., Munafò, M., & Palomba, D. (2012). Health risk factors in caregivers of terminal cancer patients: A pilot study. *Journal of Cancer Nursing, 35*(1), 38-47. doi:10.1097/ncc.0b013e31820d0c23
- Davidson, E. M., Liu, J. J., Bhopal, R., White, M., Johnson, M. R. D., Netto, G., ... Sheikh, A. (2013). Behavior change interventions to improve the health of racial and ethnic minority populations: A tool kit of adaptation approaches. *The Milbank Quarterly, 91*(4), 811–851. doi:10.1111/1468-0009.12034
- Dickson, V., Knafl, G. J., Wald, J., & Riegel, B. (2015). Racial differences in clinical treatment and self-care behaviors of adults with chronic heart failure. *Journal of the American Heart Association, 4*(4). doi:10.1161/JAHA.114.001561
- Dickson, V., McCarthy, M., Howe, A., Schipper, J., & Katz, S. (2013). Sociocultural influences on heart failure self-care among an ethnic minority black population. *The Journal of Cardiovascular Nursing, 28* (2), 111–8. doi:10.1097/jcn.0b013e31823db328
- Dickson, V., McCarthy, M. M., & Katz, S. (2013). How do depressive symptoms influence self-care among an ethnic minority population with heart failure? *Journal of Ethnicity and Diseases, 23*(1), 22-28. Retrieved from <https://www.ncbi.nlm.nih.gov/pubmed/23495618>

- Dionne-Odom, J., Hooker, S. A., Bekelman, D., Ejem, D., McGhan, G., Kitko, L.,
 ...Bakitas, M. A. (2017). Family caregiving for persons with heart failure at the
 intersection of heart failure and palliative care: A state-of-the-science
 review. *Journal of Heart Failure Reviews*, 22(5), 543–557.
 doi:10.1007/s10741-017-9597-4
- Durant, R. W., Brown, Q. L., Cherrington, A. L., Andreae, L. J., Hardy, C. M., &
 Scarinci, I. C. (2012). Social support among African Americans with heart failure:
 Is there a role for community health advisors? *Journal of Heart & Lung*, 42(1),
 19-25. doi:10.1016/j. hrtlng.2012.06.007
- Evangelista, L.S., Strömberg, A., & Dionne-Odom, J.N. (2016). An integrated review of
 interventions to improve psychological outcomes in caregivers of patients with
 heart failure. *Journal of Current Opinion in Supportive and Palliative*
Care, 10(1), 24-31. doi:10.1097/spc.0000000000000182
- Family Caregiver Alliance. (2015). Caregiving in the U.S: Executive summary.
 doi:10.26419/res.00062.002
- Fawcett, J., & Garity, J. (2009). *Evaluating Research for Evidence-Based Nursing*.
 Philadelphia, Pennsylvania: F.A. Davis Company/Publishers.
- Flores, G., & Lin, H. (2013). Trends in racial/ethnic disparities in medical and oral
 health, access to care, and use of services in U.S. children: Has anything changed
 over the years? *International Journal for Equity in Health*, 12(10), 10–30.
 doi:10.1186/1475-9276-12-10

- Foebel, A.D., Hinds, J.P., & Heckman, G.A. (2012). Caregiver status affects medication adherence among older home care clients with heart failure. *Journal of Aging Clinical and Experimental Research*, 24(6), 718-721. doi:10.3275/8475
- Gary, R., Dunbar, S. B., Higgins, M., Butts, B., Corwin, E., Hepburn, K., & Miller, A. H. (2018). An intervention to improve physical function and caregiver perceptions in family caregivers of persons with heart failure. *Journal of Applied Gerontology*, 1(1). doi:10.1177/0733464817746757
- Gewandter, J. S., McDermott, M. P., Kitt, R. A., Chaudari, J., Koch, J. G., Evans, S. R., ...Dworkin, R. H. (2017). Interpretation of CIs in clinical trials with non-significant results: Systematic review and recommendations. *British Medical Journal*, 7(7), e017288. doi:10.1136/bmjopen-2017-017288corr1
- Gabel, E., & Adabbo, R. (2011). Perceived burden of informal caregivers of a chronically ill older family member. *Journal of Geriatric Psychiatry*, 24(3), 143-154. doi:10.1024/1662-9647/a000042
- Graham-Phillips, A., Roth, D. L., Huang, J., Dilworth-Anderson, P., & Gitlin, L. N. (2016). Racial and ethnic differences in the delivery of the resources for enhancing Alzheimer's caregiver health intervention. *Journal of the American Geriatrics Society*, 64(8), 1662-1667. doi:10.1111/jgs.14204
- Graspa, E., Pantelias, K., Ntenta, E., Pipili, C., Kiouisi, E., Samartzi, M., ...Heras, P. (2014). Caregivers' Experience in Patients with Chronic Diseases. *Social Work in Health Care*, 53(7), 670-678. doi:10.1080/00981389.2014.925998

- Grove, S., Burns, N., & Gray, J. (2013). *The practice of nursing research: Appraisal, synthesis, and generation of evidence* (7th ed.). St. Louis, MO: Saunders Elsevier.
- Hamilton, H. (2016). The lived experience of African American caregivers caring for adult African American patients with heart failure. *Home Healthcare Now*, 34(4), 196–202. doi:10.1097/nhh.0000000000000359
- Helleso, R., Eines, J., & Fagermoen. (2012). The significance of informal caregivers in information management from the perspective of heart failure patients. *Journal of Clinical Nursing*, 21(3), 495-503. doi:10.1111/j.1365-2702.2011.03927x
- Heo, G. J. (2014). Religious coping, positive aspects of caregiving, and social support among Alzheimer's disease caregivers. *Clinical Gerontologist*, 37(4), 368-385. doi:10.1080/07317115.2014.907588
- Higgins, J., & Green, S. (Eds.). (2011). *Cochrane handbook for systematic reviews of interventions*. doi:10.1002/9780470712184
- Honary, M., Fisher, N. R., McNaney, R., & Lobban, F. (2018). A web-based intervention for relatives of people experiencing psychosis or bipolar disorder: Design study using a user-centered approach. *Journal of Medical Internet Research Mental Health*, 5(4), e11473. doi:10.2196/11473
- Hopps, M., Iadeluca, L., McDonald, M., & Makinson, G.T. (2017). The burden of family caregiving in the United States: Work productivity, health care resource utilization, and mental health among employed adults. *Journal of Multidisciplinary Healthcare*, 10(1), 437-444. doi:10.2147/jmdh.s135372

Hu, X., Dolansky, M., Hu, X., Zhang, F., & Qu, M. (2016). Factors associated with the caregiver burden among family caregivers of patients with heart failure in southwest China. *Journal of Nursing and Health Science*, 18, 105-112.
doi:10.1111/nhs.12253

Institute of Medicine (IOM). (2012). *Living well with chronic illness: A call for public health action*. Washington, DC: The National Academic Press.

Jha, A. K., & Epstein, A. M. (2011). Governance around quality of care at hospitals that disproportionately care for black patients. *Journal of General Internal Medicine*, 27(3), 297–303. doi:10.1007/s11606-011-1880-9

Joanna Briggs Institute. (2016). New JBI grades of recommendation. Retrieved from http://joannabriggs.org/assets/docs/approach/JBI-grades-of-recommendation_2014.pdf.

Joanna Briggs Institute. (2014). Supporting document for the Joanna Briggs Institute levels of evidence and grades of recommendation. Retrieved from <http://joannabriggs.org/assets/docs/approach/Levels-of-Evidence-SupportingDocuments.pdf>.

Joo, H., Fang, J., Losby, J. L., & Wang, G. (2015). Cost of informal caregiving for patients with heart failure. *The American Heart Journal*, 169(1), 142-148.
doi: 10.1016/j.ahj.2014.10.010

Jordan, Z., Lockwood, C., Munn, Z., & Aromataris, E. (2016). The updated Joanna Briggs Institute Model of Evidence-Based Healthcare. *International Journal of Evidence-Based Healthcare*, 17(1), 58–71. doi:10.1097/xeb.0000000000000155

- Kaizer, H. (2017). Population distribution by age: State health facts. Retrieved from <https://www.kff.org/other/state-indicator/distribution-by-age/?currentTimeframe=0&sortModel=%7B%22colId%22:%22Location%22,%22sort%22:%22asc%22%7D>
- Karakurt, P., Unsal, A., & Tanriverdi, D. (2018). Evaluation of care burden and quality of life of caregivers of patients with stroke. *International Journal of Caring Sciences*, 11(1), 529–542. Retrieved from http://www.internationaljournalofcaringsciences.org/docs/61_tarniverdi_original_11_1.pdf
- Lahaie, C., Earle, A., & Heymann, J. (2012). An uneven burden: Social disparities in adult caregiving responsibilities, working conditions, and caregiver outcomes. *Research on Aging*, 35(3), 243-274. doi:10.1177/0164027512446028
- Lee, E., DeDios, S., Simonette, C., & Lee, G. K. (2013). Family adaptation model for spousal caregivers of people with multiple sclerosis: Testing the stress-processing theory. *Journal of Vocational Rehabilitation*, 39(2), 91-100. doi:10.3233/JVR-130647
- Llanque, S., Savage, L., Rosenburg, N., & Caserta, M. (2016). Concept analysis: Alzheimer's caregiver stress. *Nursing Forum*, 51(1), 21-31. doi:10.1111/nuf.12090
- Lokensgard, C. L. (2015). A systematic literature review of effective interventions for African-American and Hispanic Alzheimer's caregivers. Retrieved from https://www.sophia.stkate.edu/msw_papers/485

- Mallett, R., Hagen-Zanker, J., Slater, R., & Duvendack, M. (2012). The benefits and challenges of using systematic reviews in international development research. *Journal of Development Effectiveness*, 4(3), 445-455.
doi:10.1080/19439342.2012.711342
- Mashayekhi, F., Pilevarzadeh, M., & Rafati, F. (2015). The assessment of caregiver burden in caregivers of hemodialysis patients. *Journal of the Academy of Medical Sciences of Bosnia & Herzegovina*, 27(5), 333-336. doi:10.5455/msm.2015.27.333-336
- McCleary, L., & Blain, J. (2013). Cultural values and family caregiving for persons with dementia. *Indian Journal of Gerontology*, 27(1), 178-201. Retrieved from https://www.researchgate.net/publication/255754376_Cultural_values_and_family_caregiving_for_persons_with_dementia/citation/download
- McEwen, M., & Wills, E.M. (2014). *Theoretical basis for nursing* (4th. ed.). Philadelphia, PA: Wolters Kluwer Health.
- McKnight, L. (2018). *Provider groups call for immediate implementation of RAISE family caregivers Act*. Retrieved from <https://www.mcknightsseniorliving.com/home/news/provider-groups-call-for-immediate-implementation-of-raise-family-caregivers-act/>
- McMillan, S.C., Small, B.J., Haley, W.E., Zambroski, C., & Buck, H.G. (2013). The COPE intervention for caregivers of patients with heart failure: An adapted intervention. *Journal of Hospice and Palliative Nursing*, 15(4), 196-206.
doi:10.1097/njh.0b013e31827777fb

- Merritt, M., & McCallum, T. (2013). Too much of a good thing? positive religious coping predicts worse diurnal salivary cortisol patterns for overwhelmed African American female dementia family caregivers. *The American Journal of Geriatric Psychiatry, 21*(1), 46-56. doi:10.1097/jgp.0b013e318263a0e0
- Mohan, M., & Fox, B. (2011). Commonwealth Fund Commission on a High-Performance Health System releases strategy for improving health care for uninsured, low-income, and minorities in the U.S. Retrieved from https://www.commonwealthfund.org/sites/default/files/documents/___media_files_news_news_releases_2011_oct_ensuring_equity_10611_pffinal.pdf
- Moher, D., Liberati, A., Tetzlaff, J., & Altman, D.G. (2009). The PRISMA group preferred reporting items for systematic reviews and meta-analyses: The PRISMA statement. *PLoS Med, 6*(7), e1000097. doi: 10.1371/journal.pmed.1000097
- Mollaoglu, M., Kayatas, M., & Yurugen, B. (2013). Effects on caregiver burden of education related to home care in patients undergoing hemodialysis. *Hemodialysis International, 17*(3), 413-420. doi: 10.1111/hdi.12018
- Muntner, P., Carey, R., Gidding, S., Jones, D., Taler, S., Wright, P.,...Whelton, P. (2017). Potential U.S. population impact of the 2017 American College of Cardiology/American Heart Association high blood pressure guideline. *Journal of the American College of Cardiology, 71*(19). doi: 10.1016/j.jacc.2017.10.073
- National Academies of Sciences, Engineering, & Medicine. (2016). *Families caring for an aging America*. Washington, DC: The National Academies Press.

- National Alliance for Caregiving, AARP. (2015). Caregiving in the U.S.: Executive summary. Retrieved from https://www.aarp.org/content/dam/aarp/research/surveys_statistics/general/2011/caregiving-09-es.doi.10.26419%252Fres.00062.002.pdf
- Pearson, A., Jordan, Z., & Munn, Z. (2012). Translational science and evidence-based healthcare: A clarification and reconceptualization of how knowledge is generated and used in healthcare. *Nursing Research and Practice*, 2012, 1–6. doi:10.1155/2012/792519
- Pearson, A., Wiechula, R., Court, A., & Lockwood, C. (2005). The JBI model of evidence-based healthcare. *International Journal of Evidence Based Healthcare*, 3(8), 207-215. doi.10.1111/j.1479-6988.2005. 00026.x
- Pharr, J., Dodge Francis, C., Terry, C., & Clark, M. (2014). Culture, caregiving, and health: Exploring the influence of culture on family caregiver experiences. *Journals of Public Health*, 2014(1), 1-8. doi:10.1155/2014/689826
- Piamjariyakul, U., Russell, C., Smith, C.E., Werkowitch, M., & Elyachar. A. (2013). The feasibility of a telephone coaching program on heart failure home management for family caregivers. *Journal of Heart and Lung*, 42(1), 32-39. doi: 10.1016/j.hrtlng.2012.08.004
- Piamjariyakul, U., & Smith, C.E. (2014). The development of cultural-specific caregiver telephone coaching program to improve heart failure (HF) home care. Retrieved from <https://sigma.nursingrepository.org/handle/10755/335415>

- Piamjariyakul, U., Smith, C.E., Werkowitch, M., & Elyachar, A. (2012a). Part 1: Heart failure home management: Patients, multidisciplinary health care professionals and family caregivers' perspectives. *Applied Nursing Research*, 25(1), 239-245. doi: 10.1016/j.apnr.2011.05.001
- Piamjariyakul, U., Smith, C.E., Werkowitch, M., & Elyachar, A. (2012b). Part 2: Enhancing heart failure home management: Integrated evidence for a new family caregiver educational plan. *Applied Nursing Research*, 25(4), 246-250. doi: 10.1016/j.apnr.2011.07.003
- Piamjariyakul, U., Werkowitch, M., Wick, J., Russell, C., Vacek, J., & Smith, C. (2015). Caregiver coaching program effect: Reducing heart failure patient hospitalizations and improving caregiver outcomes among African Americans. *The Journal of Cardiopulmonary and Acute Care*, 44(6), 466-473. doi: 10.1016/j.hrtlng.2015.07.007
- Potera, C. (2017). Bipartisan bills propose assistance for caregivers. *American Journal of Nursing*, 117(2), 13. doi: 10.1097/01.naj.0000512283.17748.48
- Punchik, B., Komarov, R., Gavrikov, D., Semenov, A., Freud, T., Kagan, E., Goldberg, Y., & Press, Y. (2017). Can home care for homebound patients with chronic heart failure reduce hospitalizations and costs? *PLoS One*, 12(7), e0182148. doi: 10.1371/journal.pone.0182148
- Reinhart, S., Given, B., Petlick, N., & Bernis, A. (2014). Supporting family caregivers in providing care. Patient safety and quality: An evidence-based handbook for nurses. Retrieved from <https://www.ncbi.nlm.nih.gov/books/NBK2665/>

- Richardson, V. E., Fields, N., Won, S., Bradley, E., Gibson, A., Rivera, G., & Holmes, S. D. (2017). At the intersection of culture: Ethnically diverse dementia caregivers' service use. *Journal of Dementia*, 18(5), 1790–1809.
doi:10.1177/1471301217721304
- Roth, D., Dilworth-Anderson, P., Huang, J., Gross, A., & Gitlin, L. (2015). Positive aspects of family caregiving for dementia: Differential item functioning by race. *The Journals of Gerontology*, 70(6), 813–819. doi:10.1093/geronb/gbv034
- Rowland, M., & Isaac-Savage, E. (2014). As I see it: A study of African American pastors' views on health and health education in the black church. *Journal of Religion & Health*, 53(4), 1091-1101. doi:10.1007/s10943-013-9705-2
- Samson, Z., Parker, M., Dye, C., & Hepburn, K. (2016). Experiences and learning needs of African American family dementia caregiver. *American Journal of Alzheimer's Disease and Other Dementia*, 31(6), 492-501. doi:10.1177/1533317516628518
- Saunders, M. M. (2012). Indicators of health-related quality of life in heart failure family caregivers. *Journal of Community Health Nursing*, 26(4), 173-182.
doi:10.1080/07370010903259196
- Schulz, R., & Sherwood, P. (2018). Physical and mental health effects of family caregiving. *The American Journal of Nursing*, 108(9), 23-27.
doi: 10.1097/01.naj.0000336407.45248.05
- Sharman, A., Colvin-Adams, M., & Yancy, C. (2014). Heart failure in African Americans: Disparities can be overcome. *Cleveland Clinic Journal of Medicine*, 81(5), 301-311. doi:10.3949/ccjm.81a.13045

- Sheet, D., Black, K., Kaye, L. (2014). Who cares for the caregivers? evidence-based approach to family support. *Journal of Gerontological Social Work*, 57(67), 525-530. doi:10.1080/01634372,2014.920606
- Söylemez, B. A., Küçükgülü, Ö., & Buckwalter, K. C. (2016). Application of the progressively lowered stress threshold model with community-based caregivers. *Journal of Gerontological Nursing*, 42(7), 44-54. doi:10.3928/00989134-20160406-0
- Stevens, K. (2013) The impact of evidence-based practice in nursing and the next big ideas. *The Online Journal of Issues in Nursing*, 18(2), 4. doi: 10.3912/OJIN.Vol18No02Man04
- Sullivan, L. T., Randolph, T., Merrill, P., Jackson, L. R., Egwim, C., Starks, M. A., & Thomas, K. L. (2018). Representation of black patients in randomized clinical trials of heart failure with reduced ejection fraction. *American Heart Journal*, 197(1), 43–52. doi: 10.1016/j.ahj.2017.10.025
- Terayama, H., Sakurai, H., Nanioka, N., Jaime, R., & Hang, H. (2018). Caregivers' education decreased depression symptoms and burden in caregivers of patient with dementia: Caregivers depression and burden. *Journal of Psychogeriatric*, 18(5). doi:10. 111/Psyg.12337
- Thomas, L. (2018). Reducing congestive heart failure hospital readmissions through discharge planning. Retrieved from <https://www.semanticscholar.org/paper/Reducing-Congestive-Heart-Failure-Hospital-through-Thomas/19c6cb0a4ca64229c7094ee61e0725274f3652ed>

- Thornton, N., & Hopp, F. P. (2011). So, I just took over: African American daughters caregiving for parents with heart failure. *The Journal of Contemporary Social Services, 92*(2), 211–217. doi:10.1606/1044-3894.4103
- Tsai, P.-F. (2003). A middle-range theory of caregiver stress. *Nursing Science Quarterly, 16*(2), 137–145. doi:10.1177/0894318403251789
- Tsai, Y.-C., & Pai, H.-C. (2016). Burden and cognitive appraisal of stroke survivors' informal caregivers: An assessment of depression model with mediating and moderating effects. *Archives of Psychiatric Nursing, 30*(1), 237–243. doi: 10.1016/j.apnu.2015.11.007
- Tucker, C. M., Marsiske, M., Rice, K. G., Nielson, J. J., & Herman, K. (2011). Patient-centered culturally sensitive health care: Model testing and refinement. *American Psychological Association, 30*(3), 342-50. doi:10.1037/a0022967
- U.S Census (2012). Facts and features: Black. Retrieved from http://www.census.gov/newsroom/releases/archives/facts_for_features_special_editions/cb14-ff03.html
- U.S. Department of Health and Human Services, OPHS Office of Minority Health. (2001). National standards for culturally and linguistically appropriate services in health care. Retrieved from <https://minorityhealth.hhs.gov/assets/pdf/checked/finalreport.pdf>
- United States Health Resources and Service Administration. (2018). National Center for Health Workforce analysis. Retrieved from <https://bhw.hrsa.gov/>

- Venetis, M.K., Robinson, J.D., & Kearney, T. (2015). Breast-cancer patients' participation behavior and coping during presurgical consultations: A pilot study. *Health Communication, 30*(1), 19-25. doi:10.1080/10410236.2014.943633
- Waligora, K. J., Bahouth, M. N., & Han, H.-R. (2018). The self-care needs and behaviors of dementia informal caregivers: A systematic review. *Journal of Gerontologist Society of America, 76*(1). doi:10.1093/geront/gny076
- Walker, L., & Avant, K. (2011). *Strategies for theory construction in nursing*. (5th ed). Upper Saddle River, NJ: Pearson Education.
- Wells, B. A., Glueckauf, R.L., Bernabe, D., Kazmer, M.M., Schettini, G., Springer, J., ...Graff-Radford, N. (2017). African American dementia caregiver problem inventory: Descriptive analysis and initial psychometric evaluation. *Journal of Rehabilitation Psychology, 62*(1), 25–35. doi:10.1037/rep0000110
- World Health Organization. (2018). International classification of health interventions. Retrieved from <https://www.who.int/classifications/ichi/en/>
- Yancy, C. W., Jessup, M., Bozkurt, B., Butler, J., Casey, D. E., Jr, Drazner, M. H.,... Wilkoff, B. L. (2013). ACCF/AHA guideline for the management of heart failure: A report of the American College of Cardiology Foundation/American Heart Association Task Force on practice guidelines. *Circulation, 128*(16), e240–e327.
- Zafar, R., Haris, M., Assad, S., Shabbir, M. U., Ghazanfar, H., Malik, S. A.,... Saleem, A. (2016). Core measures for congestive heart failure in a tertiary care setting in Pakistan. *Cureus Medical Journal, 8*(8), e728. doi:10.7759/cureus.728

Appendix A: MASTARI Data Extraction Tool

**JBI Data Extraction Form for
Experimental / Observational Studies**

Reviewer _____ Date _____

Author _____ Year _____

Journal _____ Record Number _____

Study MethodRCT ☐ Quasi-RCT ☐ Longitudinal ☐Retrospective ☐ Observational ☐ Other ☐**Participants**

Setting _____

Population _____

Sample size

Group A _____ Group B _____

Interventions

Intervention A _____

Intervention B _____

Authors Conclusions:

Reviewers Conclusions:

Note: From “A comprehensive systematic review of the nurses' perceptions of risk from exposure to emerging acute respiratory infectious diseases and the effectiveness of strategies used to facilitate healthy coping in acute hospital and community healthcare setting” by K. Yiwen, D. Hegney, and V Drury, 2009, *JBI Database of systematic Reviews and Implementation Reports* 7 (24). Copyright by Wolters Kluwer Health Inc. Adapted with permission of the author

Appendix B: JBIM Grading Chart



THE JOANNA BRIGGS
INSTITUTE



THE UNIVERSITY
of ADELAIDE

School of Translational Health Science

New JBI Grades of Recommendation

Developed by the Joanna Briggs Institute Levels of Evidence and Grades of Recommendation Working Party October 2013

JBI Grades of Recommendation	
Grade A	A 'strong' recommendation for a certain health management strategy where (1) it is clear that desirable effects outweigh undesirable effects of the strategy; (2) where there is evidence of adequate quality supporting its use; (3) there is a benefit or no impact on resource use, and (4) values, preferences and the patient experience have been taken into account.
Grade B	A 'weak' recommendation for a certain health management strategy where (1) desirable effects appear to outweigh undesirable effects of the strategy, although this is not as clear; (2) where there is evidence supporting its use, although this may not be of high quality; (3) there is a benefit, no impact or minimal impact on resource use, and (4) values, preferences and the patient experience may or may not have been taken into account.

The FAME (Feasibility, Appropriateness, Meaningfulness and Effectiveness) scale may help inform the wording and strength of a recommendation.

F – Feasibility; specifically:

- What is the cost effectiveness of the practice?
- Is the resource/practice available?
- Is there sufficient experience/levels of competency available?

A – Appropriateness; specifically:

- Is it culturally acceptable?
- Is it transferable/applicable to the majority of the population?
- Is it easily adaptable to a variety of circumstances?

M – Meaningfulness; specifically:

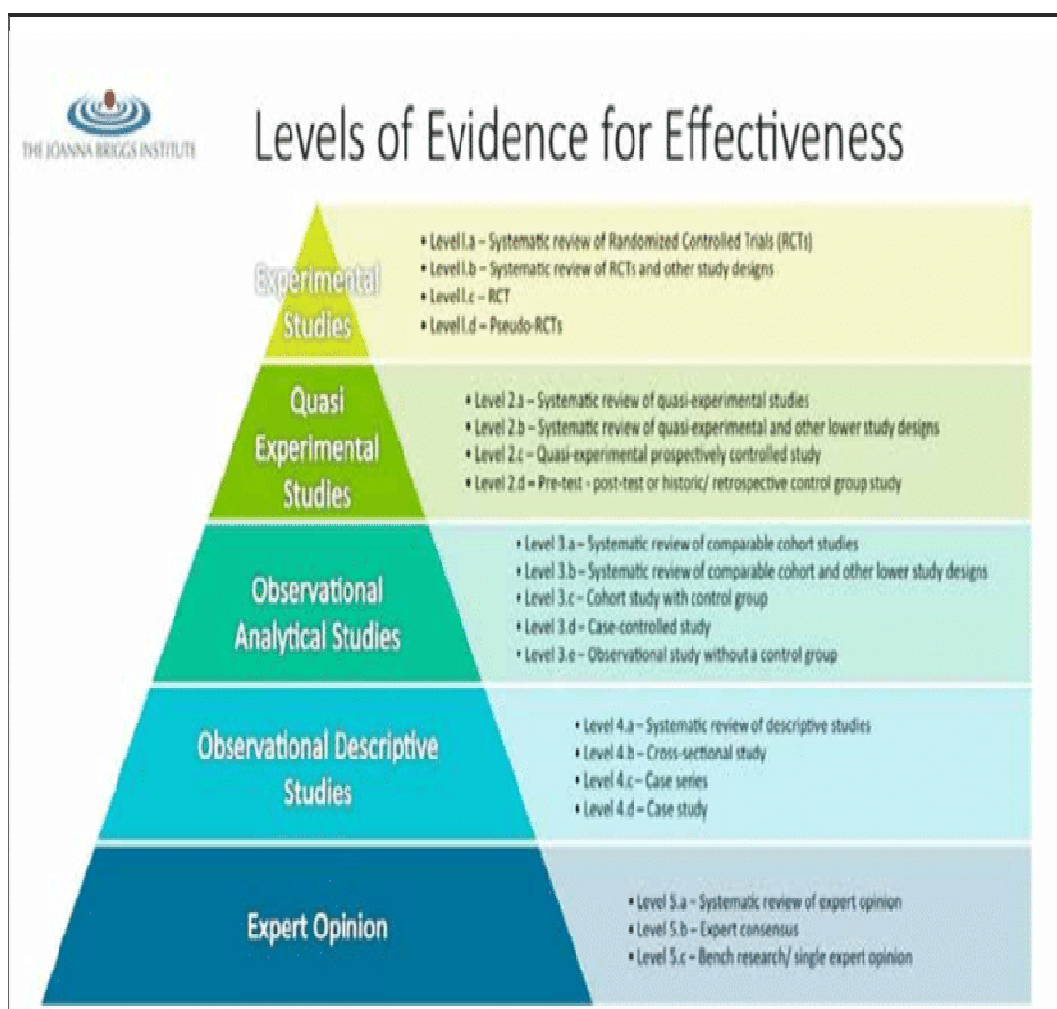
- Is it associated with positive experiences?
- Is it not associated with negative experiences?

E – Effectiveness; specifically:

- Was there a beneficial effect?
- Is it safe? (i.e. is there a lack of harm associated with the practice?)

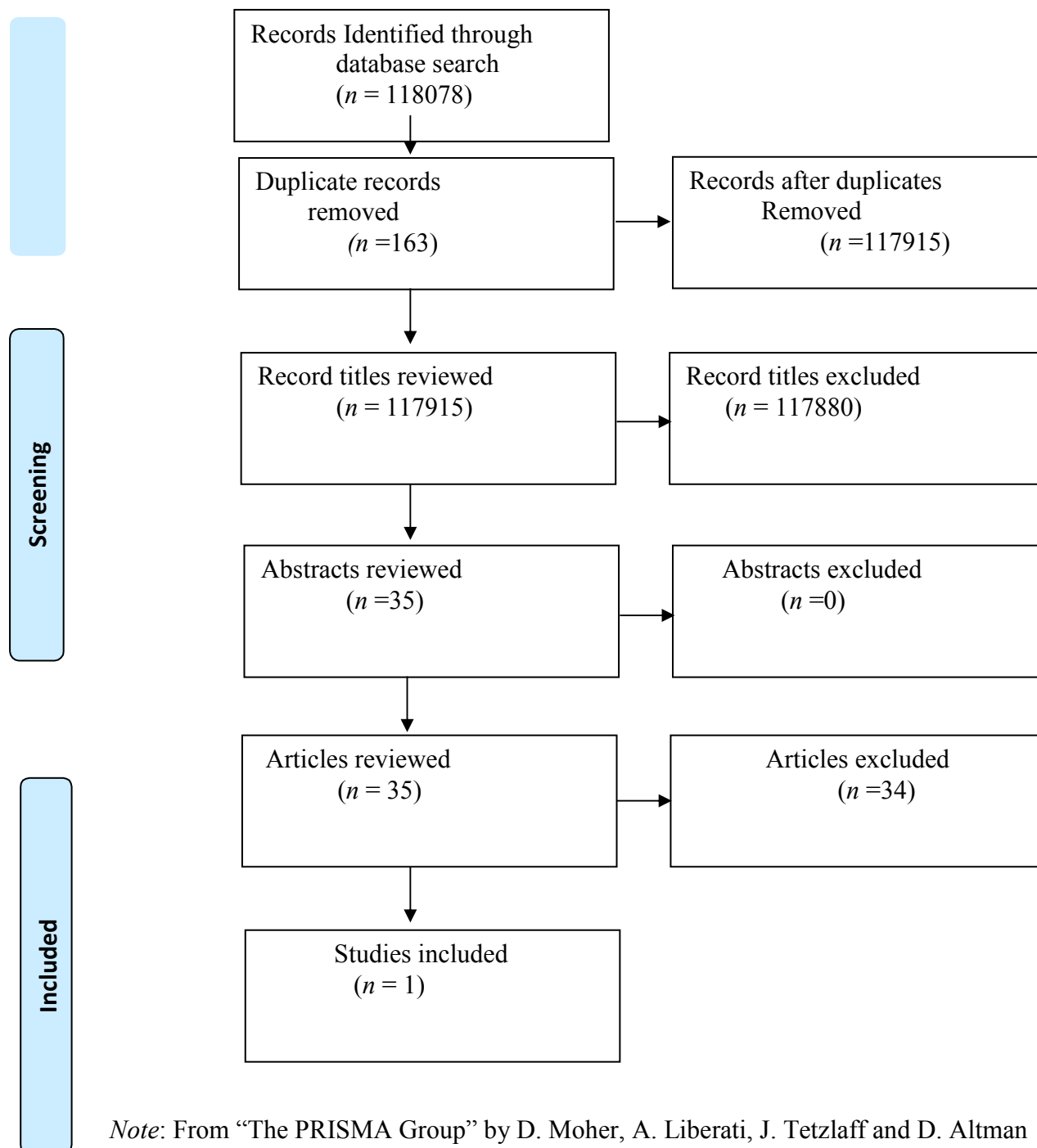
Note: From “The incidence of thromboembolism formation following the use of recombinant factor VIIa in patients suffering from blunt force trauma compared with penetrating trauma: a systematic review” by R. Devlin, L. Bonanno, and J. Badeaux, 2016, JBI database of Systematic Reviews and Implementation Reports, 14(3). Copyright by Wolters Kluwer Health Inc. Adapted with permission of the author

Appendix C: JBI Levels of Evidence for Effectiveness



Note: From “The incidence of thromboembolism formation following the use of recombinant factor VIIa in patients suffering from blunt force trauma compared with penetrating trauma: a systematic review” by R. Devlin, L. Bonanno, and J. Badeaux, 2016, JBI database of Systematic Reviews and Implementation Reports, 14(3). Copyright by Wolters Kluwer Health Inc. Adapted with permission of the author

Appendix D: PRISMA



Appendix E: Literature Review Matrix

Study	Author/Year	Study objectives	Methodology	Intervention/outcome measures	Analysis/Results	Grading
1	Piamjariyakul, Werkowitch, Wick, Russell, Vacek, & Smith (2015)	The objective of the study was to test whether a culturally-sensitive telephone coaching intervention (FamHFcare) could reduce patients' heart-failure related rehospitalizations and improve caregivers' outcome; evaluate effect size of caregivers' outcome; and evaluate the caregivers' and nurses' perceptions of the intervention.	Mixed method design with stratification and random assignment of 20 African American CHF patient/caregiver dyads. Descriptive, univariate parametric/non-parametric, and post-hoc analyses were used to analyze data.	20 African American CHF patient/caregiver dyads randomly assigned to four weeks of telephone coaching of the FamHFcare intervention.	At 6 months, compared to standard care, the intervention group had significant fewer CHF related rehospitalization, significant higher social support, and caregiver confidence and lower caregiver depression. The family caregivers rated the FamHFcare as helpful.	A

Appendix F: FamHFcure

- FamHFcure intervention (Arm 1) is culturally specific for African Americans. It includes information on all HF core measures discharge and standard care information and also includes 5 weeks of post hospital coaching on specific HF home care skills practice with a teach-back strategy.
- Each FamHFcure coaching session includes information about HF management related to specific cultural strengths and challenges. The nurse coach helps the family coordinates arrangements for transportation, housekeeping, grocery shopping, and supportive telephone contacts.
- The coach also engages local church-based lay parish nurses in HF home support, which is highly accepted in this community. FamHFcure assists caregivers in setting up comprehensive but easy-to-follow daily HF home care.
- The nurse also facilitates discussions on ways to find low-cost low-sodium foods and use recipes with low fat, salt, and calories that are culturally accepted. The FamHFcure materials on dietary sodium have been modified for cultural preferences in common African American diets.
- Applications for reduced-cost drug programs, are completed to assist with medication expenses. Coaching is given on breathlessness and comorbid symptom recognition, as well as dietary and physical activity instructions per physicians and national core HF measures guides.
- Visuals for assessing ankle edema, cyanosis, or abdominal swelling in darker skinned individuals are used. Because of African Americans' reluctance to contact

physicians, the nurse helps patients and caregivers practice monitoring and timely reporting of HF symptoms to professionals. As a reinforcement for cementing the FamHFcare information each caregiver is asked to "teach back" to the nurse what was learned in each session.

➤ Referral to mental health specialists is made for participants who are depressed and to social workers for low-income families needing assistance with medication, transportation, and monthly utility bills.

Note: From “The Development of Cultural-Specific Caregiver Telephone Coaching Program to Improve Heart Failure (HF) Home Care” by U. Piamjariyakul and C. Smith 2014. Retrieved from <https://sigma.nursingrepository.org/handle/10755/335415>